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ABSTRACT

Eight discussions of parent participation cover the following areas: dimensions of family involvement in early childhood education; the relationship of the parent, child, and professional staff; parent reactions to the identification of handicaps and their involvement in early education; parent participation in a program of behavior modification for physically handicapped children; the use of parent meetings and parent educators who visit homes to assist parents in helping children to learn; a program for training mothers to instruct their infants at home; a sociological perspective on counseling parents of handicapped children; and early diagnosis of deafness and parent counseling. (RJ)

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Exceptional Children Conference Papers:
Parent Participation in Early Childhood Education

Papers Presented at the
Special Conference on Early Childhood Education
The Council for Exceptional Children
New Orleans, Louisiana
December 10-13, 1969

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Table of Contents

Page

Dimensions of Family Involvement in Early Childhood Education 1
Donald R. Calvert

The Young Handicapped Child and the Triumvirate: Parent - Child - Professional Staff 11
Margaret H. Jones, M.D., Mary L. Barrett, M.A., Mary Delsasso, M.S.W., and Ellouise Minter, M.S.W.

Parent Involvement in Early Childhood Education 30
Audrey Ann Simmons

Participation of Parents in a Behavioral Modification Program for Physically Handicapped Children 51
James A. Oakland, Ph.D.

The Use of the Culturally Divergent Adult as a Parent Educator 59
Malcolm Garber

Training Mothers to Instruct Their Infants at Home 65
Merle B. Karnes and Earladeen Badger

A Sociological Perspective on Counseling Parents with Handicapped Children 81
Kathryn P. Meadow, Ph.D. and Lloyd Meadow, Ph.D.

The Inseparable Twins: Early Diagnosis and Parent Counseling 105
George W. Fellendorf

Preface

Parent Participation in Early Childhood Education is a collection of 8 papers selected from those presented at the Special Conference on Early Childhood Education, New Orleans, Louisiana, December 10-13, 1969. These papers were collected and compiled by The Council for Exceptional Children, Arlington, Virginia. Other collections of papers from the Conference have been compiled and are available from the ERIC Document Reproduction Service. Other collections announced in this issue of Research in Education may be found by consulting the Institution Index under Council for Exceptional Children or the Subject Index under Exceptional Child Education. Titles of these other collections are:

Early Childhood Education - An Overview
Curriculum, Methods, and Materials in Early Childhood Education Programs
Environmental Influences in the Early Education of Migrant and Disadvantaged Students
Training and Personnel in Early Childhood Education Programs

DIMENSIONS OF FAMILY INVOLVEMENT IN EARLY CHILDHOOD EDUCATION

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Family members have been involved in programs for early childhood education for handicapped children in a variety of ways. The nature of their involvement, however, has often been random or accidental, usually reflecting pressures of the immediate environment of the program, rather than the result of careful planning. Preschool education programs have frequently interpreted involvement of family members in a very limited and narrow way, viewing their role as primarily passive, or relegating them to PTA fund-raising-type activities in the backwater of the educational program. Of the 179 project proposals that had to be disapproved under the Federal Handicapped Children's Early Education Assistance Act (Public Law 90-538) in the first year of funding (1969), more than three-fourths included disapproval reasons related to inadequate participation of parents in the proposed programs.

The professional literature has dealt with the area of family member participation largely as a concern either for the services parents should receive from an early education program or for the things parents of children with particular handicaps should do to help their children. With an increasing national awareness of the need for involvement of parents in the education process, and with an increasing number of programs for the early education of handicapped children developing all over the country, there is need of concern for the broader involvement of family members in these programs. To include family involvement as a planned, purposeful part of an early education program, it is important to know the dimensions of family involvement, to know the possibilities and alternatives, and to select those most consistent with the goals of the overall program.

In developing dimensions of family involvement, we would do well to follow the interrogative approach of journalists who systematically investigate the *who*, *what*, *why*, *when*, *where*, and *how* of situations. *Who* among family members should participate, *what* is the nature of their involvement, *why* should they participate, *when* do they become involved, *where* does their participation take place, and *how* is their participation induced?

Who: Family Members Participating

Mother is not the only member of a child's family. Yet, enticed by her ready availability and the cultural expectancy that she bear the primary relationship to the child, many early education programs approach family member participation as though this were the case. Only slightly less ignored than the father are the brothers and sisters, uncles and aunts, grandparents and others living in the household. Of special concern is the decidedly female orientation of early education programs. Handicapped children, like non-handicapped children, need men and boys in their environment. With a heavy predominance of women on early education program staffs, a balance through male family member participation in the program is desirable.

The title of this paper purposely uses "family member involvement" to direct attention to family members other than parents. Some programs refer to having the whole family enrolled. The ratio of the number of family members involved in the early education program compared to the total number of family members might give information about the impact of the program on the family as a whole:

$$\text{family members involved} \;/\; \text{total family members} = \text{Impact on Family.}$$

Familial relationship to the handicapped child is less important than the amount of time spent with him and the influence over him. The nature of involvement need not be the same for all family members. Each may participate in ways which reflect his special interests and interaction with the handicapped child. Programs should reflect differential planning for different family members.

What: Nature of Family Member Involvement

From review of a large number of program descriptions and from observations of programs, a half-dozen general classes of family member involvement can be derived. These are, 1) learning, 2) working with children, 3) planning and policy making, 4) disseminating information about the program, 5) assisting in administering the total program, and 6) evaluating the program.

Learning is by far the most frequent mode of participation expected of family members by early education programs. It is often observed as a passive task but may be as active as the other dimensions of involvement. It frequently takes the form of family members attending to presentation of information through a variety of media, including reading materials, films, correspondence, records, and lectures. It may also involve discussion, either with members of other families or with professionals in special areas of expertise, for what is commonly termed counseling and guidance. Learning very frequently takes the form of observation, usually of a trained professional working with a handicapped child. The most active form of family member learning is through practice, usually supervised by a professional, working with a handicapped child. These four modes of learning for family members (attending presentation of information, discussion, observation, and practice) may all be involved in some programs but usually with emphasis on one. Their relative value for learning by family members is an area ripe for evaluation.

A second mode of family member participation is through working directly with children enrolled in the program or with the family members of other enrolled children. In work with children, the family member may take the role of a teacher's assistant, a team teacher, or an independent teacher. In working with members of other families, the role may be as one who orients the new family to the program, tells about his own experiences, or demonstrates something he has found to be especially successful with his own handicapped child. He may work with his own child or with the children of other families. If he works with children other than his own, he will need to conform to local laws concerned with health certificates and the program will need insurance to cover his activities.

A third area of family member participation, and one in which they are rarely included, is planning and policy making for the program. Family members may be involved in planning groups seeking to develop new programs or to revise operating programs. They may serve on permanent or ad hoc advisory committees for the program. Or they may serve on the regular board of directors which determines policy for the program. The appropriate degree of family member participation in policy making has been controversial in some early education programs, but more and more programs appear to be interested in including this as a role of parents.

A fourth way family members may participate is by helping to administer the program. This includes a wide variety of functions designed to help keep the program operating within its previously determined policy. Family members may receive and guide visitors to the program; they may keep records and handle other clerical tasks, design and build equipment and materials, and help maintain the physical plant and equipment. They can act as liaison with nursery schools for non-handicapped children to promote integration, or they may relate to the schools where their children will later be enrolled.

They may participate in lobbying for improved legislation for handicapped children, or they may help in fund-raising activities. Parents can often be the strongest link with community support when new funding is needed for early education programs. The constant need for such help with administering the program often leads to the development of special auxiliary organizations.

A fifth area in which family members may be especially valuable is in disseminating information about the program. Continued support by the community depends on interpreting the work of and need for the program to the public. The family member has high credibility to a public skeptical of the professional with vested interests. Family members speak to service groups, speak to other parents, interview on television, radio, or the press. They may publish newsletters and bulletins about the program and help identify the appropriate groups for dissemination.

A sixth function of family members is in helping to evaluate the program. In the planning stages, parents can participate in helping to develop appropriate goals for the program. As "consumers" of the service, parents particularly should be involved in setting goals and in helping to evaluate how well these goals are being met. Too seldom is the parent asked, "What do you expect and want from the program?" or, "Has the program succeeded in its task?" The formation of numerous consumer groups in contemporary society suggests they want to be asked.

Why: Purpose of Family Member Participation

Any early education program should do a careful appraisal of why it wants family members to participate. The three primary reasons are probably for the family member to help himself, to help the program, or to help the handicapped child. All of the various modes of participation described above can fit into these three reasons.

The family member may seek help to orient and adjust to the child's handicap so that he can understand it and co-exist with it. He may seek psychological counseling to help him through problems already caused by the presence of a handicapping condition in the child. But he also may seek participation in the early education program to feel "involved" in a relevant and worthwhile cause, or he may participate actively to assuage some feeling of guilt in his life.

The program staff may see the role of the family member primarily as helping the program through activities necessary to its operation and administration. Such activities, while genuinely helping the program, may develop into a convenient refuge, both for program staff and for parents, of appearance that family members are deeply and critically involved with their child and the program, when they are in fact working in the periphery of the program. It is doubtful that such participation is sufficient either for helping the child or for long term community support of the program.

It may be argued that any indirect involvement by family members will lead to help for the handicapped child through an improved and well supported program or more knowledgable and adjusted family members. It may similarly be maintained that any involvement of family members will to some degree serve all three purposes. Yet family participation activities of programs do differ greatly in their emphasis on one of the purposes and in their directness to helping the handicapped child. Any program should, therefore, develop its general rationale for family member involvement and consider how each of its activities bears on this basic purpose.

When: Period and Amount of Participation

In describing the participation of family members, both the periods of involvement and the amount of time spent should be included. The period during which a program is in operation may rule out participation of some family members. For example, programs operating during the work day have a de facto exclusion of breadwinning fathers, unless provision is made for meaningful involvement on week-ends or during evenings. The relative amount of time spent in participation by various family members is likely to lean heavily toward the mother because of her availability, even though she might spend less time with the handicapped child than a grandmother or older sister. It might be enlightening to compare the amount of time spent in counseling and guiding each family member with the amount of time that person spends with the child each week, to determine how efficiently time in family member counseling and guidance is being spent.

A third temporal factor is also important. With increasing experience in the program, the role of a particular family member may change over a period of time. For example, the mother may change from a listener to an observer to practice working directly with children. A father who participates minimally when he is first learning about the program may be encouraged to increase his involvement and take an active part in policy making or administration as he becomes familiar with the program. There is need for sequential growth and change over a period of time with family member involvement.

Where: Place of Family Member Participation

Early Education programs in this country are operated from three primary kinds of sites: a professional setting such as classroom or clinic, a model or imitation home setting, or from the child's home through traveling program staff members. Some programs utilize a combination of these. The nature of the primary site used by a program should be reflected in the family members that can become actively involved, the kind of participation available to and expected of family members, the purposes of involvement, and the time of involvement. Centering the program around the child's home, for example, opens up possibilities for including brothers and sisters in the program which might not be possible in a purely professional clinic.

The distance from the home of the child and the program's primary setting will also have an effect on the nature of family member participation. Typically, the families living at a greater distance would be less actively and less consistently involved in the program. Availability and expense of transportation may be critical factors. Programs may need to develop a policy of family member participation which takes into account the distance each family lives from the program.

The physical facilities available to a program should also be considered in developing a policy of family member participation. Size of rooms may preclude large group meetings. Lack of parking space for cars or lack of care for young children may discourage the participation of some families.

Families of some cultural groups may respond negatively to certain kinds of program sites, such as churches, hospitals, metropolitan locations, or certain parts of town. These factors should be taken into account in considering the population to be served by the program.

How: Inducing Family Member Participation

Some family members may be highly motivated to participate in programs through their natural high level of civic activity or through a very strong desire to give the best possible help to their children. Such people require more guidance than they do inducement to participate. There is also liable to be a number of family members who will give little or no participation regardless of inducements. But there will likely be a large number of family members who will participate if appropriate inducement to become actively involved in a program is present. In the dimensions described above, various factors have been mentioned which affect the motivation for family members to participate. The kinds of participation activities available, the time of operating the program, and the location of the program were among these. But the program may need to develop other means of inducing participation.

Some programs, particularly those sponsored by private agencies, have made some aspects of parent participation mandatory for the handicapped child to be enrolled. Other programs, charging fees for early education services, believe that most parents will participate to get their money's worth.

Another approach is to develop rewards for participation which will be relevant to various family members. Active involvement may be recognized in a number of ways, or the family member may gain community prestige through serving on a Board of Directors or an Advisory Committee. Some parents may enjoy the organizational and social activities involved in participation in the program. A few parents may become very highly motivated and become over-zealous in participation in the program to the detriment of the program or other children in the family. Some control of participation may be necessary in these cases.

To maintain the interest and participation of most family members, it is likely that early education programs will have to develop an organized and planned approach to family member involvement, and be prepared to offer appropriate inducements from time to time. Special staff may be designated to handle this aspect of the program. We do not expect young children to participate without motivation; we should not expect family members to do so, either.

Conclusions

Participation of family members is an integral part of programs for the early education of handicapped children. An organized approach to family member involvement, through consideration of the dimensions described above, can lead to planning for maximum benefit from this aspect of the program.

Active participation by family members in early education programs may well have an effect on the education programs the handicapped child will encounter later, where typically the involvement of family members has been passive, peripheral, or even discouraged. The generation of parents experiencing active participation in the education program at the early education level may not be content with such passive and peripheral involvement in the future. Their active participation in the many aspects of education may bring about a basic change in our total education system.

THE YOUNG HANDICAPPED CHILD AND THE TRIUMVIRATE:
Parent - Child - Professional Staff

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The Infant: Birth-18 months

Medically, especially in relation to chronic conditions of the brain present from the prenatal, perinatal or early infancy period, more and more often deviations from normal in developmental progress are recognized at routine examinations during infancy. Infants considered 'at risk' because of history of hereditable disease, prenatal abnormalities, abnormal behavior in the post-natal period are being followed especially carefully. (1)(2)

Previously the classical procedure of medical diagnosis involved recognition of abnormality by parents followed by consultation with the doctor. Today, "the onus of recognizing early that a child is abnormal no longer rests with the parents, but is shared by --- doctors, public health nurses and others working in public health services." (1) "The concept of diagnosis as a result of growing suspicion during the child's life increasingly replaces the concept of diagnosis as an act when the child is older and full clinical manifestations of his condition are apparent." (3)

Detection of abnormal development depends upon knowledge of normal development and expected range of deviations there from. Previously the major concern of physicians caring for infants and young children was infection - the major cause of infant death. Currently research studies are providing more and more tools for evaluations of the state of maturation of infants at birth, of their visual and auditory deficits as well as detection of congenital malformations and other abnormalities. "A very practical difference that diagnosis by increasing suspicion makes is that in many instances the child is recognized to be abnormal before the cause of his abnormality can be diagnosed." (1) Until a definitive diagnosis is possible symptomatic treatment provides the child with the best opportunity to compensate for his disabilities. In this way parents will be provided with specific training procedures to be carried out at home and will be given the support needed during the period of uncertainty pending definitive diagnosis.

Studies by many authors have demonstrated the infants ability to fix and follow an object from the newborn period on. (4)(5)(6) For example, using electro-oculographic techniques for recording, a one day old infant is shown to follow a target moving successively 10°, 20°, 30° to the right from center. More recently, by use of computor techniques, correlation of movement of the two eyes in following a target have been worked out. Though data is not yet available on newborns, an 8 month old baby was found to have a LRCC[1] of .85 to .91 in the central 20° of the visual field as compared to .87 to .88 for a normal adult. Gatev (7) describes a visual reflex appearing at about 73 days of age and disappearing about one month later. Disappearance occurred later with children retarded after asphyxia at birth. Bower states "the overall picture of perceptual development that is emerging is very different from traditional ones. It has long been assumed that perceptual development is a process of construction - that at birth infants receive through their senses fragmentary information that is elaborated and built on to produce the ordered perceptual world of the adult. The theory emerging from our studies and others -- is based on evidence that infants can in fact register but can handle less of the information an adult can register. Through maturation they presumably develop the requisite information - processing capacity". (8) In a preliminary communication entitled "Visual Agnosia in

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[1] Left-right correlation coefficent

Childhood,' Gordon discussed the likelihood of a spectrum of visual disabilities comparable to that of auditory disabilities.

Paine and Oppé (10) include, in a book on neurological examination of children, a table entitled 'Clues and Causes of Delayed Speech.' In this, findings in children with peripheral deafness, congenital aphasia, psychic deafness (autism) and those with mental retardation are compared with the normal in relation to reaction to sounds, reaction to gestures, sensory reactions, motor function and social responses.

In a recent discussion of impaired hearing in children Murphy (11) calls attention to the need of differentiating hearing and listening from other aspects of auditory response. Patterned sounds in the speech range have been found more effective stimuli than pure tones even in the newborn.(12)

Thus, with increasingly objective and precise clinical and laboratory tools it becomes increasingly possible to detect sensory defects at an early age. With more information on abnormal as well as normal postural and reflex development detection of deviations in motor maturation is also less subjective (Milani (13))(Paine (10)). For example, the relation of primitive postural and righting reflexes to the development of locomotion is shown in Milani's chart. "Motor retardation of the type associated with mental deficiency usually appears as a homogeneous shift to the left." "A wider scattering ... is usually a sign of more severe or possibly a more specific motor dysfunction, as seen in cerebral palsy."

Even in infancy objective recording of nutritive and non-nutritive sucking may differentiate the normal from the child with coordination defect in the oral pharyngeal area. (14)

Because of the frequency of drooling, eating, breathing and speech deficits in children and adults having coordination problems resulting from prenatal, natal or early post-natal causes, more emphasis is needed on detailed, thorough evaluations of oral pharyngeal function in infancy. In addition to overall deprivation of sensory experience - visual and auditory as well as tactile and kinesthetic - upper motor neurone lesions may result in abnormal function of the muscles of the tongue, pharynx and those which control the mandible. Often the hard palate is narrow and high, the jaw retruded, the tongue immobile on the floor of the mouth or lacking in normal mobility, the lips flaccid and separated, the face devoid of normal expressive movements.

To illustrate an approach to the treatment of suck-swallow problems as an integral part of the overall training program to be taught to the mother of such an infant and to be carried out at home, a film showing the development of a child diagnosed at 6 months as having pseudo-bulbar palsy will be shown. (15)

Using the type of approach illustrated in the film, of a total of 30 infants with oral pharyngeal problems as a part of the total motor deficit presumed to have resulted from early non-progressive upper motor neurone deficit treated in our unit, parent cooperation and follow through has been estimated by the therapists to be good in 19, poor in 11.

Kagan (16) states that in the first 18 months of life in the normal infant, tremendous development in both perceptual and motor development as well as in personality formation occurs. Mother-child relationship, important for the normal child, maybe more crucial for the infant with a physical handicap. The current trend toward earlier detection by the physician (pediatrician or general practitioner) of deviation from normal development brings with it the need for close cooperation a) with the therapists in application of currently considered useful procedures and in attempts to evaluate such procedures, b) with psychologists and educators concerned with evaluation of learning abilities and potential and c) with psychiatrists, psychologists and social workers concerned with parent-child relations and with social and personality development. (17)

The Toddler Age: 1 1/2-3 years

Kagan (16) highlights three major developments in this age period: the ability to locomote, the ability to comprehend and use language, the impositions of the first socialization demands by parents.

Not only in the first 18 months is parent understanding and participation in the overall management plan essential to the optimal growth of the child in all areas, but it becomes increasingly essential in the toddler years when frustrations from locomotor and/or speech deficits mount. Williams (18) calls to our attention the concept that "maladjusted behavior is learned in the same way as adjusted." He suggests that children in the "at risk" register for physical development should also be considered "at risk" for emotional development. Drillien (19) states that the "quality of maternal handling and the early environment of the child is of more significance in personality development and in causation of behavior disorders than complications of pregnancy, length of gestation or birthweight."

In the course of attempting to assist parents in helping their cerebral palsied young to develop optimal physical ability, I was asked by parents to arrange for continuous treatment by one rather than a sequence of therapists. It had been found that changing personnel often resulted in poor child-therapist relations. When it was possible, I did engage a physical therapist to work at my office. This was not enough. Children in the toddler age often cried during the short therapy sessions and mothers found them quite negative and resistant at home. The parents of one of those children later found me an office where the landlord agreed to make over a two-car garage for a pre-nursery school. Experience with this unit staffed by a physical, occupational and speech therapist working with the young children during a nursery school day period appeared to the staff and parents to result in greater total gains than had the usual outpatient program. As a result, several such units were set up in the Los Angeles area and have continued for about 15 years. (20) In these units a teacher was employed full time, an assistant teacher or aid, and part-time therapists. Medical, psychological and social service consultants participated and also parents.

For a period, the teacher at one unit (UCLA) was Mary L. Barrett, formerly Director of Nursery Education at Cornell University. She sees the role of the pre-nursery as that of an extended family living experience in a larger than individual home where each child and his parents explore a new environment. She states that the essence of the program in a pre-nursery school for cerebral palsied children and/or those with other physical defects is that the curriculum be built around individual differences and specific needs even to a greater extent than for normal children. Handicapped children are more limited in experience, have been more shielded and confined and hence have a deficit of varied multi-sensory experience. The pre-nursery seeks to give every opportunity and appropriate stimulus in a happy situation as well as to encourage independence in self care and in development of skills. As Seaver (21) points out, there is "a timeliness and a kind of sequence in the development of skills. When parents or teachers are alert for signs of readiness they can help the child ... to take the next step."

Lastly, the effectiveness of the nursery school is considered in the role of its value to parents. To many parents, the nursery school becomes a bond of hope, strength and encouragement, to some parents, a place of frustration, depression and a threat. All seek to understand, to rationalize, to learn, to communicate. The staff seeks to help each parent towards a realistic evaluation of the childs' potential, his immediate and his long term goals. To the extent it is possible, mothers are asked to assist in the nursery program. This serves the double purpose of coordinating home and school practices and providing a real learning experience for the mother and the staff.

The teacher in the pre-nursery, Miss Barrett feels, cannot understand the child except as a part of the parents and home from which he comes. She believes home visits by the teacher needed, particularly before enrollment if the child has not been outside the home. On the initial visit of parent and child to the school the teacher observes carefully play material of interest to the child, the child's communication with the parent and also the child's affection for the parent. This allows the teacher to help to make a comfortable separation of the child and parent. Miss Barrett is happier if the parent is in and out of the play area during this period and happier if the separation takes more than a week. Children who are too ready to leave their parents often are found later (1-2 weeks) not to be interested in school but to be wondering what their parents are doing. Mothers are asked in each instance, even for two year olds, to tell the child what she will be doing when she leaves.

In the nursery the teacher serves as a model for the mother. Regardleass of her theoretical and conceptional knowledge, she must be able to work with the children.

The social worker needs to have her masters degree and to have had at least 5 years in related service activity. As conceived by those who have been members of the staff, the social worker has several functions. On initial referral of the child she interviews the parents and often goes to the home as an invited guest (professional) for parents have no frame of reference to relate to the nursery school. She first assumes that the parents are well functioning adults who have special problems and need something extra to handle them. She tends to focus on the parents and their problems. No mother is prepared for a handicapped child. Many have not had the experience of a normal child in the family group. Group experience offers good learning opportunities for parents, especially parents of toddlers who are enrolled in the pre-nursery.

The staff believes that parental involvement is essential in order to develop a sense of trust in the school, to observe the teacher as a model, to find that many mothers experience the same problems, to see how their child can grow in the school environment as well as to permit staff to observe mother-child relationships and to become better acquainted with the mother. The mother needs to get some pleasure out of the experience. The teacher needs to put in time with her and not just assign her to a clean-up job.

The short film of the nursery (3 consecutive minutes) will afford a glimpse of the children, the classroom and activities as that period of time.

There is need for the development of special techniques and tools for use in the pre-nursery especially with the physically handicapped and probably also for the emotionally disturbed young children.

Miss Barrett has played a major role in the development of the two to be presented — use of a confined space and of a multi-sensory story.

The confined space, $1\frac{1}{4}$ by $1\frac{1}{4}$ feet per person, adult or child, was set-up with 5 foot plain walls to explore the hypothesis that experience in such a "little playhouse" would heighten perceptual awareness, lead to more interpersonal reactions and to an increase in communication and in purposeful activity. Two adults monitored the group and recorded activity and communication before, during and after the time (10 to 20 minutes) in the small confined area. Children's shoes were removed but only a few soft toys or scarves were provided for the purpose was interpersonal reaction rather than object play. Children improved in social awareness, peer interaction, and in social, verbal and motor activity. (21)

The hypothesis that multi-sensory training by means of a "sensory story" presenting contrasting stimuli and composed for young hemiplegic children would increase the awareness and use of the affected side appeared to be upheld by studies involving one to one presentation of single objects related to a story appropriate to the child's age and understanding. (23) Another multi-sensory story, presenting a more complex situation and utilizing a turntable as a base for four scenes involved in the story of the child's day at the pre-nursery has been developed. (24)

Too frequently, we do not talk to a handicapped child or take time to listen to his own way of communicating whether by language or expressive behavior. Too frequently, we do not listen to a child, normal or handicapped, as he expresses his awarenesses, his thoughts, his feelings concerning himself, his social and his physical environment.

In a developmental approach to language for the disadvantaged preschool child, Minuchin and Biber write, "It is at a sensorimotor level that the child has his basic experiences with space and direction, sequences in time, the nature of contrasts and similarities in the way things feel and function. It is in active interaction with the physical environment, in other words, that he begins to develop rudimentary and intuitive knowledge of the world and how it works -- and these early non-verbal schemata make possible the later growth of logical concepts and meaningful language." (25)

Senn, in exploring goals for early childhood education, states that in recent years "there has been a burgeoning of investigation into the physiological, psycho-social, and intellectual deficiences resulting from understimulation and of efforts to prevent and ameliorate deficiencies by sensory stimulation. The amount of stimulation, the timing and the involvement of human relationship are essential factors in assisting children's learning. (26)

The sensory story techniques provides a setting and time for sharing familiar experiences in a one to one relationship.

Leading Factors in Longterm Outcome

In closing, perhaps brief review of major factors considered in studies of adolescents and adults, to be responsible for achievement of maximal potential would be of importance in thinking about the training of the young children.

Curtis, a vocational counselor in attempting to find jobs for 200 cerebral palsied adults concluded that the handling by the parents in the first years of life was the most important single factor in long term prognosis. (27)

Wortis and Cooper report that expected physical achievement occurred in only 38% of a group of cerebral palsied patients followed. Achievement was rated fair in 20%, poor in 33%. Factors others than extent of physical handicap appeared to be important in prognosis. (28)

In a survey of adolescent cerebral palsied in Isreal the following personality characteristics were found:

Concentration poor	70%	
Adjustment to handicap poor	53%	
Social maladjustment	44%	
Emotional imbalance	48%	
Work attitudes poor	38%	
Little independence	75%	(29)

In an adult study in New York, again with the cerebral palsied, the authors found prognosis related to the following factors:

Exaggeration of handicap
Relation to others
Emphasis on normal classes
Social independence
Parental understanding
   "   attitudes
Isolation
Early total rehabilitation (30)

Summary

This presentation has stressed the importance of sensori-motor evaluation of infants and young children and assistance to parents of these children in techniques of handling problems resulting from early deviation from normal development.

It has indicated some recent research studies which assist in more objective early diagnosis.

It has indicated roles of parents, teachers and others as well as the role of the physician.

It has given examples of two new approaches to training in the $1\frac{1}{2}$-3 year age group - use of confined space and multi-sensory story.

Lastly, it has called attention to factors reported to be related to long term prognosis - factors indicating the major role of personality development and work habits in determining the long term outcome.

It has been my pleasure to participate in a program in which the "professional educator" (30) is taking a new look at his role in learning problems in the very young. (31)

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PARENT INVOLVEMENT IN EARLY CHILDHOOD EDUCATION

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While educational programs for parents have existed in this country for as long as there are records, the educational "discovery of infants" and their parents is a more recent event and the concept of parent involvement is particular to this decade.

Originally, much emphasis was placed on giving parents increased understanding of their handicapped child, so that they might be better able to guide him to his optimum development. Actually assuming the role of the child's teacher seemed to be an integral facet of the parent's education. Gradually, however, the scope of interest has widened to take in an understanding of the parental role, since this is a very critical developmental period in the child's life.

The infant's capability for assimilating and processing information in his very early years as well as his capabilities for emotional and physiological involvement has been clearly documented. The growth and development of the infant into his adult potential are much too important to be ignored.

Parent involvement is now seen as more than information-giving. It must aim toward increasing the understanding of parents at many levels of learning and through many kinds of experiences so that they will achieve further individual growth and develop greater competence in dealing with their children.

Of course, these goals must be applied realistically. Parents will gain from involvement in a variety of different ways, depending upon their need and readiness. We may not be able to bring about drastic changes in the personalities of parents or in child-care practices which have their roots not only in individual knowledge but in the parents own upbringing. But we must provide the parents with greater knowledge of children, of the handicapping condition of their child, of themselves, of family and community relations in order to enable parents to alter some of their own practices.

In many ways the greatest need of a handicapped child from the beginning is a parent who can understand his problem and adjust to it. He needs parents, who as a result of this understanding, also foresee what his needs will be.

It is sad, that the vast majority of parents, at least initially, have no true concept of the educational situation connected to the handicap. As professionals, we are apt to discuss hearing impairment, mental retardation, cerebral palsy and other handicaps with implicit and frequently naive assumption that the general population understands what we are talking about. We need to spend a considerable period of time talking about specific problems to parents at a level they understand. This needs to be done even if we end up so oversimplifying the technical aspects that they seem elementary.

It is most important that this counseling be given at a level which makes it comprehensible and effective. Often this means providing a great amount of basic information, giving the basic principles underlying the habilitative procedures. Too many parents have attempted to cope with a handicapped child for many years without having anything approximating a true understanding of what really was the educational difficulty.

Another major area needing immediate help is the parents coping with problems of hour-to-hour, day-to-day management. Too often we assume that because we have suggested ways of giving language, or have prescribed didactic exercises, we have really provided for the follow-through and therefore care. Frequently the overall suggestions for the child's day may be more worthwhile than to fragment it into parcels for speech and other activities.

There is much evidence from the study of children brought up in institutions, such as orphanages, that an impoverished environment, in which there were few toys, few contacts with adults and generally low levels of stimulation, led to retarded intellectual and social development. (2) The conditions in institutions are, however, exceptional and likely to be extreme. While we know little at the present time about the amount of variation in the stimulation that children receive in the average family setting, it seems clear that we need to see that the handicapped child's day is meaningfully spent.

Under ideal conditions the parents assume responsibilities for different aspects of the child's learning. Generally, the mother satisfies the child's needs and administers to his comforts. She provides security and understanding. The father, on the other hand, provides opportunities for his child to socialize through games, conversation, and other, often more physical activities in which male interests and feelings are projected. However, these ideal conditions do not exist in all homes.

Most research in the parent-child interaction assumes that there is a direct and discernible relation between parent variables of behavior, attitudes, and personality and child behavior and personality variables. This might well be an oversimplification.

It might very well be that the parents and children influence each other in a two-way fashion. The child's behavior may shape that of his parents as well as theirs shaping his. Normal children by the age of three months seem to have a very strong control over their parents. It has been said that the mother is a puppet to her three-month-old puppeteer. If that puppeteer is in fact a handicapped child it seems plausible that he may shape some patterns of behavior entirely different from those of a normal child.

Rheingold (9) listed the home activities recorded in a normal environment in order of magnitude as:

1. Holds
2. Talks
3. Talks to
4. Feeds
5. Looks at face

as contrasted with those performed in an institution which were:

1. Holds
2. Feeds
3. Looks at face
4. Talks to

It becomes readily apparent that if the handicap is that of hearing impairment, the second and third activities of the mother might soon be extinguished. She may receive little or no reinforcement from deaf infant. He may not coo, smile or do any of the reinforcing stunts that mother needs.

Many parents have not had the necessary training for this type of stimulation. Contrary to the notion that parenting is instinctive, evidence is accumulating that it, too, is taught. From animal experiments it has been demonstrated that offspring denied "mothering" in their infancy developed maternal behavior themselves that was completely abnormal, ranging from indifference to outright abuse. Those primates entrusted to wire surrogate mothers were inferior to those with cloth surrogates, but both were poorer mothers themselves than primates who had had their real mothers. (5)

It is readily apparent that if the child's handicap is a speech or hearing problem there is some degree of breakdown in communication. This breakdown can lead to difficulties in interpersonal relationships which lead to further breakdown in communication. The parent contributes to the child's problems and visa versa. It is a two-way channel with the parent neither entitled to total credit nor to total blame for his child's behavior. (11)

Reactions of Parents:

Certainly, the climate for the child's progress is set by the family's reaction or responses to the knowledge of the handicap. The very nature of their responses will affect the child's emotional as well as his cognitive development.

As we observe the reactions of parents to their handicapped children, these often seem to be divisible into stages similar to those deliniated by Shontz. (10) I do not mean to suggest that all parents go through multiple stages. Unfortunately, some may remain in one or the other indefinitely. The first general parental reaction to the tragedy of a handicapping condition is that of shock. This seems reasonable when you realize parents are dealing with the catastrophe of a significant life-long handicap.

It is a period of numbness when the problem seems to be perceived sharply and clearly with a great deal of docility. Lowell (7) reports that at this stage parents retain little if any of the important crucial information given them. Regrettably, some parents are so overcome by the knowledge that they never get beyond this emotional state.

It is understandable that many parents pass from this first stage to one of panic. They seem unable to plan or to understand the situation and frequently manifest their inability to deal with the situation. If one observed parents only at this stage he would witness rejection which is even physical at times. The realization of the handicapping aspect is extremely difficult at this period for most parents.

It seems appropriate that at this stage, too, for parents to doubt the accuracy of the diagnosis. Naturally parents will desire another opinion, and competent consultation is frequently beneficial in establishing the parents' necessary peace of mind. Their wish to shop about for various opinions is surely understandable. If it is recognized and properly directed it can be useful. If, on the other hand, it leads to indiscriminate "shopping", it is almost always unfortunate. (3) In situations where there is wide diversity of professional philosophies of management, it is frequently wise to advise the parents, accordingly, so that they will not become confused by a multitude of opinions. Certainly, parents should be protected against inaccurate, unnecessary, unwise or overly optimistic attitudes. By all means we must be forthright with them.

The stage following panic is that of retreat or denial. When the situation becomes overwhelming, many of us try to escape. We may even deny that the problem exists. So, too, do many of the parents. When suggestions are given for their action, some parents quickly exhibit an inability to do them. They want someone else to do everything. "You teach him." "You care for him." "I don't know how." "I don't have time." Avoidance seems to be the key word at this phase.

If the professional person is patient, wise, cooperative and capable, he will help the family through the periods of insecurity until the parent acknowledges the handicap. It is then that the parents report it has been as if they had "just buried a good friend." Shontz describes it as "true mourning". As parents acknowledge the child's handicap, you can almost witness them rolling up their sleeves and plunging into the task.

This does not mean they have overcome their own personality conflicts. They may still be sad and even bitter. They may still question why it happened to them. They may indulge in scapegoating, each other, the doctor, the circumstances, or even the agency rendering service. The latter is a natural target in the parent's search for a scapegoat. I might suggest, however, that the vulnerability of parents to scapegoating may lie in the fact that the specific cause of a child's handicap might be known. Be that as it may, the reasonably healthy parents are usually able to recover from the shock, the panic, the desire to escape and eventually reach the final stage of adjustment and in some cases even acceptance. It is necessary for them to arrive here, but more necessary, even critical, for their child. Only when this stage is reached can the teacher and/or counselor, the child and his family begin to cope with the handicapping conditions in an optimal manner.

There are parents, though, who "accept" the problem but have expectations which are too high and others who have those that are low. Michaels & Schucman (8) describe mothers, who not only accept the child's handicap but appear to approve of it. These low expectancy parents view the child's dependency as giving meaning to their own lives. Their efforts are bent toward discouraging the child's acquisition of self-sufficiency. The unhappy consequence of the high expectancy parent is the child's inability to please him. Repeated exposure to failure and parental disapproval has serious effects on the child's emotional stability. It is extremely important that we channel the expectancy of the parent to the potential of the child.

Then too, there is the guilt prone parent who tends to view the handicapped child as a symbolic punishment for real or imagined wrong doing or even thinking. That parent may have not wanted that child. She may have sought the wrong medical advice during pregnancy. In general, the heavy burden of guilt carried by parents seems to be tied to an assumption that they somehow are always responsible for what has happened to their child. It is interesting that parents who feel relatively certain that their child's condition was caused by rubella or who have adopted their child do not describe the intense feelings of guilt as do the others.

It is quite common, too, for us to see another much-favored defensive mechanism of almost obsessive overprotection used by mothers of handicapped children. Whether it springs from a mother's deep unconscious need for absolute dependency of her child upon her or her own guilt feelings, it must nevertheless be dealt with before the child can mature.

It should further be noted that the total family milieu may be of such a nature as to alter entirely the paternal or maternal attitude toward any individual child. Sickness of the mother or in the family members, economic crises, change of job or location, or changed marital relationships all have their effect. Children born at such times of crisis within the family setting naturally put strain on the parents' attitude. If these crisis are brought on because the child is handicapped, certainly relations can be affected.

Importantly, in the family setting are siblings who need consideration and inclusion in the total picture. A series of studies relating to this problem in regard to retarded children in the family has been done by Farber. He found greater adverse conditions resulting from high degree of the dependency and superordinate roles eventually assumed by the normal siblings irrespective of the handicap child's place. The handicapping condition affected not only the parents but the entire family as well. (4)

Home Demonstration

If we turn specifically to our attempts to understand the implications underlying the variations of parental attitudes, it becomes apparent that our procedures for getting them involved must be individually based. At Central Institute for the Deaf we have had a program for parents of deaf infants since 1958. Over that period of time our program has changed somewhat.

Originally, the parents came together to get the best information they could about their child's hearing problem, what they could expect of their children and how to deal with his handicap. Soon it became clear that they needed that and more. They had needs themselves, as parents. They had their own attitudes, feelings, and expectations. They had goal setting problems. They needed to focus on their role as shapers of their child's behavior and in particular his language behavior.

With young babies there is no question of formal teaching situations, the only effective way is to adopt a normal approach. All parents have many opportunities in their homes, moment-by-moment, for shaping linguistic and cognitive behavior. There is dressing, washing, feeding, playing. However, parents need help in translating what they are told to do into their own home. Therefore we initiated another aspect in our program and that was a Home Demonstration Center which is a real home in appearance.

If you saw it, you would perceive an old house with two apartments under its roof, like any on the block. The apartments are furnished in "Sears Early Desperation" and are far from prestigious, but they are warm, inviting and comfortable. The first floor apartment has a living room, dining room, kitchen and bedroom. On the second floor is a kitchen, a living-dining room, a bedroom, a child's room and a bath. All appliances work with some degree of regularity. The refrigerators, while not laden, are adequately full and similarly the cabinets and closets. In short, nothing is contrived. There are no offices, nor office or school paraphernalia around. These are in the Institute itself a short half-block away.

Into this setting come the parent and child for an hourly session with a teacher of the deaf. During this time she attempts to help them learn to seize every opportunity for language input. Since our emphasis is upon parents being first-rate-parents not second-rate-classroom-teachers, we use only experiences that each mother would be doing in her particular home. The tasks are of the regular household, child care variety. They are the typical daily tasks of the average home.

In her own home the parent is the teacher in the broad sense of the term. Therefore in our Home Demonstration Center she demonstrates how well she is progressing while the real teacher makes appropriate comments. It is obvious that the latter has to be skilled in creating an atmosphere of ease, transforming apprehensiveness into creative energy and helping the parents feel the need for interaction with their child.

Because we do not want the children to grow up unstimulated in well-furnished pleasant rooms filled with a variety of expensive, meaningless toys as is often the case, we try to provide basic perceptual sensory and therefore cognitive experiences. These experiences have verbal labels associated with them which in turn assist in the storage of the language e.g. vocabulary, and concept. Through his perception the child develops appropriate concepts and vocabulary connected to the experiences which have features in common. Mediated with similar language the concept develops and the language is absorbed. The child, therefore, receives the data by which to induce the rules. For example, "washing" is a concept which has linguistic form: wash hands, wash face, hair, wash someone else's face, hands, etc. wash dishes, pots, pans, silver, wash clothes, wash the car, wash the dog, wash the windows, wash the floor, etc.

The implements are soap, sponge, washcloth, mop. The features in common are water, soap, and rubbing action but the most important feature they have in common is the word "wash".

We hypothesize the word "WASH", experienced in a variety of situations can be more readily learned by the child than the word experienced even many times in only one situation. There are some interesting data available which confirm this hypothesis. (6)

The appropriateness of the activity is part of our direction. (We have even had doubts about such things as our storing milk in a jar, when most children use a carton.) Part of this is discussed with mother prior to her demonstrating with her child the task or tasks she has planned for the hour.

Frequently advice on good "mothering" is given. Certainly good mothering techniques get reinforced. When she does something to get her child involved, captures some of his language output, anticipates his need, we reinforce her with praise or commendation depending upon her need. Sometimes, we even have to show the mother how to care for her child physically. We may have to "teach" tricks of toilet training, feeding, bathing and even of clothing. If mother can't cope we must help her.

Needless to say siblings come with mother whenever possible. While this may create havoc, for the teacher, this after all is the true situation that faces mother at her home. We strive also to have contacts with the father as well as the mother. As was noted earlier, the presence of a handicapped child is likely to intensify family stresses. One effect may be to decrease communication between the parents each of whom may have developed very different views of the child. If we can set the pattern of forthright discussion about what the child did, can do, might do, and will do, we hope we might focus their attention and even discussion into meaningful channels.

In seeing parents the teacher never assumes that a conference in which the parents nod their heads in apparent assent necessarily represents real understanding. The intense emotional bond between parents and child may preclude rapid attitude change. Genuine change is a time-dependent phenomenon resulting from continuous exposure of the parents to reality oriented situations. In these sessions with the teachers, parents are encouraged to be themselves, to disclose their own thoughts and feelings. As Beasley (1) stated,

> to the extent that parents themselves are granted acceptance and respect, they will be more free to give this to their child. . . . ... Since the problems of a child in language and speech originate and exist in an interpersonal setting, modifications of this environment may be highly important if change is to take place. p. 319

Group Education

Fundamental to the parent's understanding of the handicapping condition is his knowledge of the handicap. The program of parent groups continues as an essential part of the Institute's services. At these sessions the subjects are: language development, hearing aids, behavior modification, genetics, hearing. Some of the speakers have been adult deaf, the director and the principal of Central Institute, child psychologist and other parents.

Before we think about what parents gain from experience in groups we raise a question. What is it that they really need? There are some universal trends that we have observed. Parents want, first of all, up to date and accurate scientific information, in language they can understand, regarding their children's handicap, the effect that disability may have on the usual chart of normal child development, the emotional aspects of the handicap, and the way the handicap may affect the children's personalities and behavior. They want to know very practically what they can do to help their children develop to their best capacity, and what they may expect this capacity to be. In other words, they want to know how to manage now and what they have to look forward to.

These are the questions they often bring first to professional people, with a very strong sense of urgency. It is only later that they reveal that they need to know more about themselves, about their own widely conflicting but normal feelings, and their own special level of tolerance of the demands that are put upon them. They need to have help in recognizing both where they are weak and where they are strong so that they can turn to appropriate services for help as they are needed. They also want to know the effect of a handicapped child on the family as a whole - - - the strain this places on the marriage, the effect on other children as they are growing up.

Surely some of the information parents need can be made available to them through the printed word, and in lectures at large meetings. Yet we must always remind ourselves that these "formal presentations" have their limitations, that parents will take from such reading and talks only what they are able to take from them and that they may react to this material in ways that one cannot predict in advance.

We must not underestimate the impact of one parent upon other parents in these group situations. In order to study this we had a person trained in this sort of thing attend all our parent's meetings and take transcripts. We excluded from the meetings the audiologists and "parent teachers". There was quite a ventilation of attitudes such as frequently doesn't come out in the interaction between the professional person and the parent. This aspect of parent involvement will be covered by Mrs. Lillie so I shall not delve into it in any greater depth.

A variety of group experiences, however, needs to be provided in order to capture the parent at whatever stage of crisis reaction he might be. For example our mothers' group meetings range from small to large. One group is the beginning mothers, another the continuing mothers. A third group is the combination of the two. These all meet once a month as does the entire parent group. Unfortunately our fathers' group gets together only every other month. It should be noted that the parents proceed very quickly to enter into significant discussions and a rather immediate sense of identification and from one parent to another takes place.

Conclusion

Parents of handicapped children, like their children differ greatly. Not only do they have the regular variable factors of culture, education and mentality but they bring added variables created by the handicapped child's existance. These variables cover a wide spectrum.

Many forces impinge upon the parents at any given time. Rarely do two or more sets of parents function at the same level at any given time. Therefore I propose that each family group be treated as a separate unit. Appropriate individual guidance needs to be given to each family. Nevertheless, because they are all coping with a similar problem I also suggest that opportunities be provided for group instruction and discussion.

The primary purpose of the parent involvement is to reach their handicapped children early and effect change. What parents do is still a matter of empirical determination.

Current data, sparse though they still are, clearly establish that there is no one regimen or sequence of events which will optimally benefit all infants. The degree and kind of relationships between various types of experiences in early life and subsequent behavioral performance is not at present known. Nor is there adequate theory to guide those who have to make decisions concerning the kinds of experiences to give infants. But it does appear that shaping parental behavior is a direction. At least the converse has been demonstrated by various studies which have shown that the earlier in life maternal deprivation started, and the longer it lasted, the worse were its results. If deprivation started in early infancy and lasted for as long as three years, the damage could never be undone said one investigator. (2) In order to prevent the added handicap of deprivation and capitalize upon the critical time of infancy, we need to intervene as early as possible.

Summary

In summary, there has been a change in emphasis with parents from didactic course work to total involvement. This involvement has shifted from parent becoming an instructor to parent being a teacher in the broad sense. Knowledge relative to the handicap is still essential but parents need help in parenting. They need to recognize the opportunities offered constantly in the home and the impact of their child on them and the family. The professional people need to be alert to the range of emotional periods through which parents pass. Recognizing the levels, the professional people must accept parents at the stage at which they are and move from there. A suggested program of a home demonstration was described. Not to be neglected also are group opportunities for ventilation and exchange. As the author of "Children Learn What They Live" said years ago:

> If he lives with acceptance,
> he learns to love.
>
> If he lives with approval,
> he learns to like himself.
>
> If he lives with friendliness,
> he learns that world is a nice place in which to live.

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Participation of Parents in a Behavioral Modification Program for Physically Handicapped Children

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Grateful acknowledgment is extended to the National Foundation - March of Dimes for their support of this project with grants #C-12 and #CRCS-39. Copies of this paper may be secured from James A. Oakland, Department of Pediatrics, University of Washington School of Medicine, Seattle, Washington, 98105.

Parents of a physically handicapped child have an enormous task confronting them, for not only must they do the usual tasks of parenting, but they are also given additional assigments, such as physical therapy exercises to carry out each day, and the usual tasks are complicated and made more difficult by the handicap. Out of these experiences, parents learn early that they must do many more things for their physically handicapped child than they would for a normal child, and their child learns that many things must be done for him. This "active parent-passive child" arrangement, while useful in many ways, later becomes an impossible situation. Parents complain that the child is not "motivated" to do the things he can do - like dressing and undressing, daily hygiene, feeding, and so on. They see the child sitting in his wheel-chair, passive and helpless in the face of their expectations that he do some task, and this raises mixed feelings of guilt and resentment. Are they expecting too much from a handicapped child? The result is often that the parent ends up doing it for the child, yet feeling vaguely manipulated. Efforts by many parents to break this pattern often result in a power struggle with ill feelings on both sides, and little success in establishing a new pattern.

The picture we often encounter in the clinic, then, is, first a passive, dependent child, who learned this style out of multiple experiences of being cared for by necessity - he couldn't do the job himself because of his handicap, and, secondly, an active parent who must do many more things for his child than other parents, but who gradually gets "locked-in" to this way of parenting his handicapped child and who is seemingly unable to gain the cooperation of the child in creating a different approach.

When we encounter this (and it is very frequent), we have proposed a behavioral modification program as a means of changing the pattern of behavior between parent and child. This simply involves the use of rewards and punishments, selected and applied in a way that maximizes the possibility of change.

Certainly, this approach is not new; it has probably been the typical approach of parents for all of human history. This, of course, is an advantage, in that we are not introducing something unique, only taking what the parent is doing and clarifying the procedures. Thus, if the reward is defined in terms of what the child finds rewarding, not what the parent thinks is rewarding, the desired change is much more likely to occur. If the reward is given immediately after the desired behavior rather than some time later or as a promise (and veiled threat) prior to the behavior, again likelihoods are increased. If the desired behavior is broken down into very small steps and the child learns each step well, being rewarded for this, the end product will more likely be what the parent hopes for. These principles almost seem common sense, yet it is amazing how many violations of them occur among parents. Certainly, the model is well-supported in psychological research, and in the practical applications in schools, clinics, hospitals, homes, and so on.

The procedures typically followed with each of the families we see are as follows: An initial appointment is made with parents and child, when the problem behaviors are identified and the program described. Arrangements are made to gather data in the home. Usually a home visit is made between the first and second appointments, when the therapist obtains data on the frequency of the behaviors and the contingencies involved, and gives the parents the book, Living with Children, by Patterson and Gullion, to read. This book presents the principles of behavioral modification in an easy-to-read fashion. At the next appointment, the therapist goes over the book with the parents making sure that the concepts are reasonably well understood. Rewards (or reinforcers, as we call them) are selected and the program details worked out so that the attack on target behaviors is begun immediately. Subsequent appointments are arranged to look at the data collected by the parents and to work out problems.

The following are representative examples of our work. They were selected because they illustrate many varied aspects of the approach (though formal discussion of these aspects will be limited).

The first child, whom I shall call John, is a five-year-old boy, with a diagnosis of meningomyelocele (spina bifida). This is a defect in the development of the spinal column occurring 8 to 12 weeks after conception. Because of the failure of the complete closure of the primitive neural tube, these children are born with a defect in the vertebra and spinal cord which leaves them without adequate innervation of the lower trunk and extremities, together with frequent secondary complications, such as hydrocephalus, urinary tract infections, and orthopedic problems of the back and legs.

John comes from a family of four. Father, age 30, is a college graduate in engineering; mother, age 25, a high school graduate with additional secretarial training, but who is not presently working outside the home. John has a sister two years younger than he. The family has adapted fairly well to the fact of John's disability, although the fact of his borderline level of intellectual function has only been partly assimilated.

John is typically, lively, alert, and observant of his environment, quickly noting and imitating the verbal behavior of others. Consequently, he has a repertoire of quite adult and "cute" phrases, which elicit laughter and approval, particularly among adults who encounter John for the first time. Unfortunately, he has become very adept at using these phrases to avoid performing difficult or otherwise undesirable tasks. For example, when an intelligence test was administered to him, John would often respond to questions with such phrases as, "Let's see," "I don't remember that, darn it," "I'm going home now," "I goofed, darn it," "Don't ask me that now," "I'm trying to think," and so on; in a twenty-minute period during test administration, John emitted 35 such interfering phrases, usually placing his head between his hands and looking away from the task. While these behaviors are comical, they become increasingly frustrating to someone working with him toward a defined goal. With John about to enter kindergarten, it was clear that such behaviors were an impediment to John's adaptation there and to his prospective learning experiences. Hence, the behavioral modification program had as its target two areas: 1. limiting his expression of disruptive phrases which would be incompatible with attention to, and execution of, a task; 2. strengthening such pre-academic skills such as counting, color-naming and so on, which would enhance John's probability of success in kindergarten. Because of the short time involved prior to beginning at school, the program was carried out in the clinic. One parent was always present, and observed (and later modeled) the procedure.

Discussion with the parents revealed their disapproval of the use of anything except social reinforcers, such as praise and approval, with John, i.e., they seemed to feel that the use of toys, food, and concrete rewards were inappropriate in the training of children. Consequently, social reinforcers were used with the idea to test out John's responsiveness to them. Typically, one would proceed from primary reinforcers, paired with social praise, to secondary reinforcers, such as tokens later traded for toys, to social praise alone; with John we proceeded almost in the reverse order. Social reinforcers produced no consistent behavioral change. Secondary reinforcers in the form of penciled tallies traded for colored stars were also not particularly successful. A primary reinforcer in the form of raisins, used at the suggestion of Mother, was inadequate in that John satiated on these too quickly. It was then decided to return to pencil marks, which could, when a few were accumulated, be traded for pennies, and when a few pennies were accumulated, he could buy things at the "store," i.e., a shelf of novelty toys which had high interest value for John and were purchased by his parents. This system was applied to the tasks presented to John and the result was that, within four weeks, John was performing well in such things as color-naming, counting, identifying letters of the alphabet, pre-reading skills, and so on.

To eliminate (or slow down) the disruptive verbalizations, an extinction procedure was used in which the therapist turned her body away from John and made no response for several seconds following such phrases. While this was initially effective, it appeared that John received a great deal of reinforcement from being able to manipulate the therapist into turning her back. It was then decided to begin rewarding the incompatible behavior of attending to the task in addition to the above extinction procedure. This was quite effective.

John began school and, by his parents' and teacher's reports, did very well. His classroom behavior was typically within acceptable limits, and maintained, largely because the parents continued the procedures after termination at the clinic.

The second child, whom we shall call Randy, is a five-year-old boy with cerebral palsy, hydrocephalus and mental retardation. He is fairly well known to the clinic as a result of periodic visits, and to the psychologists because of intellectual evaluations. His mother is an intelligent, serious woman in her forties. She has only partly assimilated the fact of Randy's physical and mental handicaps, and her adjustment includes devoting great quantities of time and effort towards Randy. The father is a pleasant, easy-going man who works long hours and is not deeply involved in the daily family activities, but who is fond of and indulgent toward his wife and child. Older siblings are married and away from home. The family lives approximately 100 miles from the hospital, a fact of particular interest in that the behavioral modification program was carried on largely by telephone.

At the time of a clinic visit, the mother voiced her distress about Randy's eating patterns and her lack of success with toilet training. An appointment was arranged with the behavior therapist, at which the time the situation was assessed, and the Patterson book given the parents to read. At the second appointment (both parents present), the therapist obtained a detailed behavioral description of the problem area of greatest concern to them, in this case, toilet training; reinforcement principles, including successive approximation, were explained and illustrated in terms of the problem, and a step-by-step program set up. Emphasis was placed on flexibility in application, in that they could make any changes consistent with the principles.

The specific problem was that Randy would neither sit nor approach either of the potty chairs in the home, and, if forcibly placed there, would cry loudly and continuously until Mother took him off. Steps to modify these behaviors include the use of praise as a reinforcer, shaping approach behaviors until he would readily sit on the potty chair for at least 15 minutes.

The next contact was made by phone nine days later. Randy was now sitting on the chair and showing no signs of distress. One creative innovation had been worked out: Mother noted Randy's fear of the potty chair, but not of another chair of similar size and shape. Suspecting that the hole in the chair was significant, she covered it with a paper towel until Randy was readily acceptant of it, then removed it, a step which Randy could take relatively easily. Further steps were planned, always emphasizing the principles involved. Data collection was instituted at this time. At the second phone conversation, ten days later, Randy had had several successes with toileting. Record-keeping was improved, practices inconsistent with the principles were noted, with suggestions for corrections, and general questions were answered. The third phone contact, 20 days following the second, revealed that Randy was now doing very well with his toileting, rarely wetting his pants. The program was now expanded to two additional problem areas and at the fourth call, eight days later, and the fifth call, one month later (three months after setting up the program), things were progressing well. At this point, orthopedic surgery was planned, which involved a week's hospitalization and six weeks of casts on his legs. Randy's mother was quite distressed, feeling this would result in the loss of all the learning which had occurred. Since delay of surgery was impossible, efforts were made to work around it and to allay Mother's anxiety. Two months post-surgery, Mother reported that Randy was doing well; she had used a paper cup while he was in casts and no decrement in toileting behavior had occurred. The program was now expanded further to cover additional problem areas and Randy's mother was placed on her own, insofar as implementing the program, with the option of calling if she needed a consultation. Two subsequent contacts revealed that, aside from minor problems, desired changes had occurred and subsequent performance was consistent. Interestingly, Mother typically focused on remaining problem behaviors, rather than the successes achieved.

The third child, whom we shall call George, is a seven-year-old boy, with the same diagnosis as John, meningomyelocele. He comes from a relatively large family - there are four older children, two brothers and two sisters, and one younger brother. Both parents are high school graduates; Father is an insurance broker. George is a quiet and dependent child of average intelligence, who was seen for the purpose of building self-care behaviors and independent functioning. The initial interview with the family made apparent their confusion over knowing whether George was truly capable of but inadequately motivated toward performing certain tasks, or whether he lacked the skills involved to execute the tasks. Close coordination was arranged between our program and the physical and occupational therapy programs. In the latter, George's present self-care skills would be assessed and any unlearned skills taught. The physical therapist also visited the home to ensure that everything would be safe and conducive to George's independent functioning.

A self-care rating system, modified from the Kenny Self-Care Evaluation Form (Schoening & Iversen, 1965), was devised in consultation with the physicians and physical and occupational therapists who determined what could realistically be expected of George. His mother was taught to make the ratings.

One of the major obstacles to independent functioning appeared to be the intervention of both Father and Mother, who found it easier to help and prompt George than to allow him the leeway to attempt his own self-care. Because of this, it was difficult to determine what George would do if not aided by his parents. It was emphasized that, in order to assess his present level of autonomy, it was quite necessary that both the parents refrain wherever possible from helping George.

A week's baseline data was collected and, from this, two areas of concern were identified. The first area was that of washing face, hands, and arms, and brushing his teeth each morning. George usually dallied 15 to 20 minutes, and usually had to be prompted and nagged before giving up his play and completing the tasks. The other concern was over George's slowness in coming to dinner, and his dallying and playing with his food during the mealtime. When called for dinner, he frequently delayed 10 to 15 minutes before coming to the table, and when he did arrive, he would sit for some five minutes before starting to eat. His mother said it took constant coaxing and reminding to get George to finish his meal. Usually it took George 15 minutes longer to eat than the rest of the family.

While George's mother felt the morning dallying was "quite tolerable" at the time, the dinnertime behavior was quite frustrating. Dessert was chosen as an appropriate reinforcer for proper eating behavior. If George came promptly to the table when called, and was able to pace his eating so that he finished with the rest of the family, he could then have dessert. Followup ten days later showed this to be very effective. George had consistently come to the table immediately upon being called, and was always the first one of the family to be finished.

Unfortunately, following this success, this family did not continue with the program, stating they were too busy with company and vacations at that time. We are hopeful they will become reinvolved.

Two points may be presented. First, behavioral modification is a technique of sufficient refinement to make the tasks of parenting, more particulary of a physically handicapped child, immensely easier. In gaining a more appropriate response style in the learning situation with John, in getting George to stop procrastinating and dallying around mealtimes, and in securing toilet training for Randy, we have found the behavioral modification is potentially a very powerful approach, and even can be done, on occasion, with minimal personal contact with the family (cf., Randy). Certainly, the basic approach of rewarding and punishing behavior is age-old, and probably universally used in some version. Nevertheless, such recently articulated and clarified concepts as successive approximation, reinforcers being defined by their effects on the subject, reinforcers administered immediately following the behavior to be modified, and so on, often make the difference between success and failure in achieving a desired behavior from a child.

On the other hand, behavioral modification appears deceptively simple, and therein is both its strength and weakness. For example, the selection of reinforcers for John was a relatively long and involved process which required not only a healthy knowledge of the behavioral modification approach, but also considerable information about John himself (mostly supplied by the parents) and some shrewd intuition about what will likely work. Further, there is sometimes a complex intertwining of variables which are difficult to sort out, for example, when a child's helpless behavior is rewarding or gratifying to a parent. The claim is not, however, that it represents the solution to any and all problems involved in the care of physically handicapped child, but that it is one technique, which, if used with consistency and sophistication, will resolve many difficulties a parent encounters.

Secondly, we have ceased to view the child primarily as an individual with certain personality characteristics, and strengths and weaknesses in abilities and life styles. Instead, he is one member of a family which has certain patterns and structures, and that by responding to the whole family, we increase the possibility of the child maximizing his potential in life, we decrease the chance of poor success in the goals for the child, and we do not overlook the needs of the mother, the father and the siblings. Concretely, this means that in clinic, we try to see, or certainly find out about all family members and take them into the treatment planning.

A third point. We are aware that the need is far beyond the resources of our clinic, even potentially. People from four states (distances of greater than 600 miles occasionally) come to the clinic; yet the technique extends over time and requires periodic contact which eliminates all from our program who live beyond the relatively small area around our clinic. Further, the number of clinic personnel we have for this is quite insufficient for the need, even for those in the limited geographic area. A related problem has to do with whether such a program should be carried out by clinical psychologists in a clinic setting; parents often have understandable fears about the psychiatric implications of the treatment. A logical alternative which would solve both problems cited, would be to incorporate into the developing programs for early childhood education, the behavioral modification approach with the emphasis on teaching the skills to parents to help them be more successful in the tasks of parenting. I urge its serious consideration.

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THE USE OF THE CULTURALLY DIVERGENT ADULT AS A PARENT EDUCATOR

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The three-way attack of Gordon's Florida Parent Educator Model involves the parent in the home as one of its focal points. Actually, the parent is a key element in educating the child from the standpoint of those who have developed the Florida Parent Educator Model. Change the parents and you change the child. Develop effective techniques of stimulating the child and you may develop a child who will be more effective in school. Involve a parent in the process of teaching her child and you will probably have a more capable child. And so, one of the major thrusts of this program is aimed at developing a more effective mother, or mothering one. This model looks toward changing the mothering one.

The mothering one's attitude toward school may be changed by a variety of experiences she has with schools and school people. Parents have come to the Parent Advisory Council Meetings to find out what the program means for their children. The Parent Advisory Council (P.A.C.) is a group of parents who represent the families in a given Head Start or Follow Through community. They assist in the selection of school programs as well as in the determination of who is to be parent educators. Their role is to advise the school district or project directors. Since these are parents, sensitive to the needs of their children and the demands of their community, the recommendations they make to school people are considered very meaningful and very important.

By encouraging parents to meet and discuss what is happening to their children, it is possible to influence the attitudes of mothers and mothering ones. Trust of the schools can be fostered when parents understand the goals of a school program. When parents participate in the school program, it is possible that prior negative attitudes toward school can be changed.

Sometimes early resistance in the parents has to be overcome. Take the case of one grandmother with ten children who was invited to a P.A.C. meeting. When she was asked to come to the meeting, her immediate response was that the school meeting conflicted with a church meeting. Further discussion revealed that any night of the week was a "meeting" night. She would always be unavailable. However, her initial resistance toward coming was surmounted. Having come to an evening meeting, she was shown some of the work of her four-year-old granddaughter. She was asked about the strengths of this child. These strengths were to be used as starting points in the educational program which was to be tailored for her granddaughter. This was made clear to her. The teachers and parent educators told her of the progress her child was making. She appeared delighted. A parent educator visited her two days later with a task for her to teach her child. The door was opened wide. A task which reflected the individual needs of the child was presented. The parent surrogate became aware that each week a new and distinctive task would be brought into the home. A new more positive view of the school may have been in the making. This parent spoke of her older children, and said she wished some of them had had the opportunity which Head Start was presenting the grandchild. She seemed to feel that this weekly home task might really help her child. This was something, within her own power, that she could do to help her child. Doing such meaningful work can possibly change the way a person sees himself. It can also give one a feeling of mastery or control over what is happening around him. It may even create a feeling of trust in the schools. Such attitudes can lead to greater involvement in school activities.

During evenings when parents are involved in Community Action Program Meetings they may be also exposed to the kinds of activities in which their children are involved. Parents may gingerly experience foot painting, finger painting, modeling clay, etc.

Parents may also help out with some of the other activities that are entailed in evening meetings. One of our Head Start programs in Chattanooga has enlisted its parents to make drapes for the classrooms and also to come into the classrooms and read. Another one of our communities had a parent demonstrate ethnic cooking techniques to children. The Jacksonville Head Start program had a parent volunteer make pizza pies for the children. What such involvement may do is create better attitudes toward the school. Parents can get the feeling that they are masters of their own fate and to some extent they may pass this on to their children. The respect which is often a veiled fear that some parents have for school can become a respect which is moderated by trust toward the school, and esteem for oneself. This is most certainly a desired outcome of the Florida Parent Educator Model.

The mothering one can sometimes be the father, if the father is the one who most of the time assists the child in learning at home. Neither natural parent need be the one who teaches the child tasks. Grandparents, aunts, brothers and sisters, even friends of the family may teach the child in the home. Preferably, one person in the home will consistently work with the child. A parent educator may work with a father, showing him how to administer a task to his child. The parent educator may be concerned with the way the parent administers the task as well as the content of the tasks. Sometimes, the task requires some rather elaborate materials which are brought into the home. Often materials, available in the home are used in tasks. The development of a better idea of what a circle is can be the goal of a task. The parent might be asked to teach the child to make a circle using different shapes, such as crescents, or straight lines. Of considerable importance might be the way the parent goes about teaching the child. Can the parent be taught to allow the child to make a mistake without punishing the child? Is it possible that the parent may even teach the task by generating feelings of success in the child? These are also some of the objectives in taking tasks into the home. The model makes an attempt to change the teaching behavior of the parent--a difficult yet crucial task. To fulfill this requirement the parent educator must be well aware of the goals of each task.

This will only be accomplished when a close and wholesome communication can be established between a teacher and her parent educators. Our model calls for two parent educators per classroom. The teacher needs to be concerned that the parent educators know how to administer the task and the reason for giving the task. She emphasizes why the task is important. That way she can answer a parent's questions about the value of doing such things in the home.

The parent's concern for what and how the child is learning increases as the parent becomes more actively engaged in teaching the child. More opportunities for learning at home may be provided. Concern about the way the child talks and thinks may developm Expectations for the child's success may grow. The child's accomplishments may systematically be rewarded. This is a process which could affect the parent as much as the child. A need to achieve in the parent may be fostered by the success experiences gained from working with the child. The parent might seek more schooling so that he can better teach his child.

An enriching academic experience can be triggered in a Head Start or Follow Through Program such as this. Mothers can meet together and begin to learn how to assist their children in learning to write. They can gain self-confidence by talking to one another and the teacher in a group.

In fact, group discussion and consideration of social issues can be a stimulant which might lead to a parent finishing high school, or going on to college.

Mothers have come to the school to talk with the teacher and parent educators about enrollment in an adult education program. Mothers have learned to trust the parent educators. Mothers have confided in their parent educators. Mothers have developed strong enough feelings of mastery and a powerful enough self-concept to begin to enrich their academic experiences.

The parent seems to be changing and the Florida Parent Educator Model is contributing to this change. Not only has the parent succeeded in helping her child, she has also succeeded in helping herself. If the Florida Model can assist in changing those who mother Head Start children, it will have become a significant weapon in the war against poverty. This is one objective of the model.

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TRAINING MOTHERS TO INSTRUCT THEIR INFANTS AT HOME

Merle B. Karnes and Earladeen Badger[1]

The educational program for disadvantaged infants that I am describing today is one that was developed over a seven-month period and implemented by mothers who had undergone an intensive training program conducted by professional staff. The impetus for this pilot research project was derived from an earlier study (Karnes, Studley, Wright, and Hodgins, 1968) conducted with mothers of three- and four-year-old disadvantaged children who were not enrolled in a preschool program. Although this was a short-term study (11 weeks), the results clearly demonstrated that mothers can be effectively involved in direct intervention with their preschool children at home. While Schaefer (1969) and Kirk (1969) have developed successful tutorial programs for infants, the ratio of professional staff to infants makes the application of these programs on a large scale impractical both financially and in terms of available personnel. This study, then, was based on the premise that mothers of disadvantaged infants can be trained to more effectively stimulate the intellectual and language development of their infants. Such an effort, if successful, would (1) extend the number of children reached by limited professional staff with minimal budget, (2) stimulate the mother's awareness of the education needs of her infant and her role in meeting these needs, (3) affect positively the educational prognosis of other children in the family as the mother incorporated her training into her role as mother, (4) develop a sense of dignity and worth as the mother demonstrated self-help capabilities, (5) provide a setting where family problems related to school failures and disappointments but beyond the mother-infant focus could be openly discussed, and (6) contribute to the training of indigenous leadership by encouraging these mothers to become involved in the agencies for educational and social change within their own community.

METHOD

Recruitment

Twenty mothers with infants between the ages of twelve and twenty-four months were recruited from the economically depressed neighborhoods of Champaign-Urbana, a community of 100,000 in central Illinois.[2] Staff workers at the offices of Aid to

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[2] The original intent had been to include a control group of twenty infants and mothers; however, an adequate number of mothers able to participate could not be recruited, and the attempt to maintain a control group was abandoned.

Dependent Children and the Public Health Department were the primary referral sources. In addition, an interviewer canvassed certain acutely disadvantaged sections of the city to locate disadvantaged families new to the community or otherwise unknown to the referring agencies. Sixteen of the twenty mothers who comprised the training group were ADC recipients. The families of the remaining four children met the OEO poverty definition acceptable for Head Start admission.

During these initial contacts, the mother was asked if she were willing to attend a two-hour class each week where she would be instructed in teaching techniques to use with her infant at home. In order to make appropriate baby-sitting arrangements for her children, she would be paid $1.50 an hour to attend these meetings. Transportation to and from the meetings would also be provided. She was asked, further, to agree to apply these teaching techniques with her infant for a period of time each day. She would not be paid for this work-time at home, but the toys used to implement the instructional program would be given to her baby. Finally, it was explained that the infant would be tested at home before and after the program to determine how successful she had been as a teacher.

Although the mothers readily acknowledged the importance of education to their children, they did not recognize their contribution to that enterprise. The suggestion that they could learn ways to stimulate the mental and language development of their babies at home was received with skepticism. Needless to add, many mothers agreed to participate in the program with only a limited commitment. Generally, it might be fair to characterize the mothers' initial acceptance of the program as follows: They wanted their children to have a better education than they had had and were favorably impressed by the educational opportunity offered their infant regardless of how inadequate they may have felt about their own participation as a "teacher."

Background of the Mothers

After enrollment had stabilized in November, the group of twenty included eighteen Negro and two Caucasian mothers. Three of the Negro women were grandmothers who were included because they assumed the primary responsibility for the infants. The two white mothers and four of the Negro mothers had been born in the North; the others had migrated from the South, principally from Mississippi but also from Georgia and Arkansas. The ages of these mothers ranged from 19 to 56 years, with a mean age of 29.4 years. Their educational levels ranged from 6 to 12 years, with a mean of 9.2 years. These mothers had from 2 to 12 children, with a mean of 4.9 children.

Public assistance through Aid to Dependent Children was the total or partial support for sixteen of the families included in this study, and the fathers were absent from all but two of these homes. Six of these mothers worked on a part-time basis (domestic day-work) to supplement ADC funds; three had stable full-time employment (a hotel maid, an aide in a nursing home, and a drug store cashier), and one attended a beauty culture school on a full-time basis. In the families of the three participating grandmothers, the mothers of the infants were full-time students. Four of the families in this study were self-supporting. Three of these families represented intact marriages. Two mothers were employed full-time; one worked a sixteen-hour day at a factory assembly-line job and an evening food service job and the other supported herself as a food caterer. With only one exception (the family in which the mother worked a sixteen-hour day) the annual income of these families did not exceed $4000.

Initial Characteristics of the Children

The mean chronological age of the twenty infants who participated in this study was nineteen months at the time of the initial intelligence test, with a range of 14 to 26 months. Nine of these subjects were female, 11 were male; 18 were Negro and two were Caucasian. The initial mean Cattell IQ of this group was 97.6, and IQ scores ranged from 79 to 120.

Intervention

To encourage discussion, the twenty mothers were divided into two groups of ten which met separately throughout the program. Two staff members conducted the weekly two-hour meetings over the seven-month period of the study. One staff member functioned as a group leader while the other served as a recorder. After the meeting, both staff members evaluated in writing the content presented and the interactions among the members of the group. In addition, they made monthly (more often when necessary) home visits to reinforce the teaching principles introduced at the meetings and to help each mother establish a positive working relationship with her baby. These visits also provided staff members an essential observation of the appropriateness of the infant curriculum as well as their success in communicating teaching strategies to the mothers. In all cases, these visits were welcomed by the mothers.

In general, the weekly meetings were divided between child- and mother-centered activities. The first category included the presentation of educational toys and materials with an appropriate teaching model and required strong staff leadership. The mother-centered activities involved group discussion directed toward child-rearing problems in today's society but was intended to foster a sense of responsibility in the mothers for themselves, their families, and the community in which they live. That portion of the meeting often involved minimal leader participation so that the group would provide its own vehicle for attitude change through interactions among the members.

Eleven educational toys were chosen as the instructional media for the intellectual and language stimulation of the infant but were, of course, equally important as the media in which a positive interaction between mother and child occurred. In addition, crayons, scissors, play dough, chalk and slate, inexpensive books, a lending library of thirty wooden in-lay puzzles, and simple object lotto games were provided. A child's table and chair and a plastic laundry basket for toy storage were supplied as conditioners of good work habits. These materials were chosen through an evaluation of those used in the earlier infant tutorial program and were selected to offer a wide range of experience in sensory-motor as well as conceptual and language development. While the books were primarily intended to encourage language interactions between mother and child, all of the program toys created opportunities for verbal development. As the leader demonstrated teaching techniques with each new toy, she used key words which the mothers were to use and which they were to encourage their children to say.

Certain principles of teaching were repeated often at the weekly meeting and encouraged during the home visits.

1. If you have a good working relationship with your child, you can become an effective teacher. A good relationship is based on mutual respect.

2. Be positive in your approach. Praise or acknowledge the child's success in each new task, even when the child simply tries to do as he is instructed. In correcting a mistake, minimize it. Show the right way immediately; have the child attempt the task again and praise him.

3. Break a task into separate steps. Teach one step at a time, starting with the simplest. Do not proceed to the next step until the child is successful with the first.

4. Introduce one toy at a time. Put one toy back in the laundry basket before presenting another. With beads or toys with many parts, use a container on the table to teach order and to prevent spills.

5. If the child does not attend or try to do as instructed (and you are absolutely sure he can do what is asked), put the toys away until later. Try again when he is ready to work. Do not scold, beg, or bribe. This time together should be fun for both of you.

The instructional program for the child developed as follows:

1. The table and chair set and plastic laundry basket were considered essential in encouraging organization in the home and with the child. Mothers were instructed to work with their babies at the child's table and with the child on his chair. Initially, work periods were only ten minutes but increased as the child's attention span lengthened and as the selection of toys increased.

2. Each mother collected or was given a set of five seriated cans. Introducing two cans, she stressed the words big and little. She taught her baby to stack, saying, "Put the little can on top of the big can." Then the cans were inverted: "Put the little can in the big one." When the child successfully performed these tasks with two cans, the mother increased the number until he was able to perform both tasks with five cans. The use of cans preceded the nested boxes which were distributed later.

3. Initially, mothers were instructed to remove the graduated rings from the spindle and arrange them in order on the table. The child was to place the rings on the spindle in order. When this format was followed, even the youngest baby was successful, and the graduated rings proved to be a good first toy for developing a sense of accomplishment.

4. In introducing snap beads the mother stood behind the child's chair, clasped her hands over his, and repeated the motions of push and pull by snapping and unsnapping the same two beads. She exaggerated this movement, repeating the key words. When the child approximated these motions, he was ready to try to snap the beads without help. Later, he had to be helped again to learn to move the hand that held the chain of beads up to the next bead.

5. Although five geometric shapes were to be placed in their proper holes in the form box, each mother began with the easiest shape, the circle. Calling the shape by name, she helped her child insert the circle until he could do it by himself. Other shapes were added one at a time.

(The Nested Cans, the Graduated Rings, the Snap Beads, and the Form Box were introduced during the first six meetings. The first two toys helped to develop a sense of success; the other two required patience from mother and child. Help from the mother was particularly needed with babies under twenty months of age. Since most of the babies had an attention span of less than twenty minutes at this stage of the program, four toys and two simple picture books were adequate materials for daily at-home work sessions.)

6. Stringing beads was a more difficult task than snapping beads. Mothers needed to demonstrate many times and, as with the snap beads, helped their children by standing behind their chairs. Babies under eighteen months were not ready for this toy, but most of the children were completely successful with this task between the ages of twenty and twenty-two months.

7. Masonite Shapes in various colors and sizes were presented initially to emphasize form and size. Color was not stressed, and this toy served as an extension of the form box and of the concept of big and little introduced with nested cans. Mothers were instructed to stress the words circle, square, big circle, little circle, etc. They were encouraged to improvise verbal games such as "Give me the big circle. Put the little circle in the box."

8. Only two nested boxes, big and little, were presented at first. In addition to the stacking and inverting tasks introduced with nested cans, the child learned to cover the little box with the big box, "to hide the box." Later, when working with several boxes, the mother prearranged them to insure the child's success.

(At the end of the third month of the program, older children were performing fairly successfully with all of these toys. Several were attending for as long as an hour, and the mothers were encouraged to repeat the complete program of toys daily.)

9. The pounding bench, busy box, and music ball were distributed to mothers the week before Christmas and were described as "fun toys." They were not to be kept with the program toys or played with at the table and chair; rather, the baby could play with them whenever or however he chose. Mothers who complained that their babies didn't want to stop working when they put away the toys were instructed to use the fun toys as transfer toys. The mother was to put away the program toys when she decided the session was finished and to give her baby one of the fun toys as a substitute. For those babies who valued the time with mother rather than the toys, this substitution was not very successful.

10. The lending library of thirty wooden in-lay puzzles (3-12 pieces) was initiated during the third month of the program. Mothers of younger babies kept the same puzzle for two or three weeks, but other mothers exchanged puzzles on a weekly basis.

11. During the second half of the program, language development was increasingly emphasized. Mothers received a list of antonyms with examples of how to teach them to their babies. The teaching of prepositions was demonstrated with program toys. Several simple finger plays were also taught. Books such as The Three Little Kittens and Mother Goose Nursery Rhymes stressed dramatization in story-telling. These kinds of activities were

not enthusiastically received by the mothers, perhaps because they were self-conscious about their own speech patterns, and the two white mothers provided most of the favorable response to these activities. All of the mothers, however, enjoyed teaching body parts to their babies and some were successful with as many as 10-15 parts of the body.

12. All of the babies enjoyed playing with play dough, scissors, crayons, and slate and chalk. Although these materials were offered to the child during the work period so that his mother could supervise, their use was relatively unstructured. Other than teaching their babies to make a circle by going "round and round" with a crayon on a large newspaper and with chalk on the slate, the mothers were encouraged to allow their babies to express themselves freely with these materials. Several of the older babies learned to use the scissors very well and to show control with large crayons. A home project which proved very successful in stimulating language was a picture scrapbook, a loose-leaf notebook with durable, heavy-grade paper. The mother or older children in the family cut pictures from magazines and catalogs which the baby was able to identify by naming or pointing. These pictures were pasted in the scrapbook, a source of pride and accomplishment shared by mother and child.

13. A set of 10 wooden blocks, the learning tower (5 graduated, plastic cylinders), and Unifix Cubes (10 one-half inch interlocking plastic cubes) were introduced near the end of the program to demonstrate transfer of learning to the mothers. Mothers were requested to provide no instruction and to observe the reactions of their infants when presented with these toys. In order that a staff member could also observe these reactions, these toys were distributed during a home visit. Staff and mothers were delighted to see that most of the babies stacked and inverted the plastic cylinders from the learning tower as they had the cans and boxes. They were able to join the interlocking cubes with the same skill they had acquired with the snap beads.

14. Four kinds of Object Lotto Cards were rotated during the last month of the program. The pictures on the cards were familiar to most of the babies, and the older children quickly learned to match the cards to the pictures on the large lotto card.

The mother-centered aspect of the weekly meetings was not planned by the staff alone; rather, the group response to previous material guided the selection of discussion topics. The leader was prepared to introduce a new topic at each meeting but was willing to change the agenda when a more relevant topic was brought up by one of the mothers. Among the topics which provoked meaningful discussion were child discipline, birth control, and the generation gap. On occasion, pamphlets or magazine excerpts were distributed for reading prior to discussion sessions. Several films

("Guess Who's Coming to Dinner?" and "Palmour Street") and speakers (a Black Power advocate and a family planning expert) were included as were a trip to the public library to provide cards for all mothers and to explore the resources of the children's library and a visit to a demonstration nursery school. After group identity had been established, discussion sessions were sometimes replaced with role playing. (One mother played the role of a teenage girl who wanted to quit school and get married. She came home late to find her mother and grandmother waiting up for her and announced her decision to marry. From this point, the acting members and the group as a whole explored various aspects of the generation gap.)

Evaluation Procedures

Interim data were to be collected and evaluated at the end of the first and second years (Spring, 1968; Spring, 1969). When the children reached the age of four (Spring, 1970), postdata were to be collected and the study terminated. Three major comparisons were to be made: (1) A comparison at the end of each of the three years of the study between the twenty children whose mothers had been trained to teach them at home and a comparable group whose mothers had not been provided with this training (2) A comparison at the age of three years between the children whose mothers had been trained to teach them at home and a group of middle-class children (3) A comparison between the children whose mothers had been trained to teach them at home and the infants who were tutored by professional personnel in the preceding Kirk study. Because of the termination of funding, this study continued less than a year and these longitudinal comparisons cannot be made. Since it was not possible to maintain a control group, that interim comparison cannot be made; neither can an interim comparison be made with the infants tutored professionally, since the length of tutorial intervention doubled the intervention of this study at its termination.

Initially the twenty infants were administered the Cattell Infant Intelligence Scale and were to receive the Stanford-Binet Intelligence Scale at the end of the first year of intervention. At the termination of this study (seven months), eight infants, according to the judgment of the examiner, were incapable of being tested with the Binet and were administered the Cattell. The primary intent of the initial Cattell was to match an experimental and a control group, and comparisons between test-one Cattell scores and test-two Binet scores were not considered. Assessment of children at this age is difficult and tentative at best, and these data in the absence of a control group provide little information on the development of the infants.

A more appropriate evaluation of this truncated program can be made through a consideration of the data recorded by staff members during the monthly home visits and after each weekly meeting. Data on mother participation was gathered on five variables. Absences from the weekly meetings were recorded. The levels of participation at the meetings were rated (1) exhibits leadership (2) exhibits interest but remains essentially a silent participant and (3) exhibits indifference or boredom. Mothers were rated ego-centered if their major concern at meetings was over personal problems rather than the educational goals of the program for their children. In an anonymous ballot mothers indicated whether they desired to participate in a consecutive, second-year program. The final assessment of mother participation was whether she was able to extend the activities of the program through innovative use of materials, through the preparation of a picture book designed to stimulate the child's labeling skills, through extending her teaching skills with other children in the family or neighborhood.

Mother-child interaction as it related to the instructional program was assessed in three areas. The mother's teaching relationship with her child was rated (1) to indicate a highly effective teaching relationship with appropriate positive reinforcement (2) to indicate a teaching relationship inappropriate at times (too little or too much positive reinforcement, too high or too low expectations for child performance) and (3) to indicate an essentially negative teaching relationship (difficulty in praising the child, short-tempered, inconsistent). The interest and attention span shown by the child working with program materials were rated during home visits. A positive rating indicated that child and mother worked agreeably with program materials for increasingly sustained periods. Finally, the child's spontaneous verbalization was rated as appropriate and adequate or conspicuously reduced while working with program materials.

Child performance was assessed during home visits on nine activities: snap beads, form box, string beads, masonite shapes of different colors and sizes, nested boxes, puzzles, books, identification of body parts, and picture lotto. The child was rated positively if his use of these materials was appropriate and essentially correct. Since two items (snap beads and nested boxes) were mastered by all children, they were eliminated from further consideration in evaluating differential performance.

RESULTS AND DISCUSSION

A preliminary examination of the observational data indicated that the age of the infant at the initiation of the program and whether his mother was employed full-time were of governing importance. Although working mothers were not excluded during recruitment, staff members noted early in the program that these mothers were less able to devote time and energy to attending the weekly meetings and to implementing the program's goals at home with their children. For this reason, the data for the six mothers who were employed on a full-time basis and for their children are presented separately. A further examination of the data within the group of nonworking mothers (N=14) indicated that the age of the child at the initiation of the program was of considerable importance to many of the variables assessed, and, therefore, the data for the younger children (13 - 19 months) are presented independently of the data for the older children (20 - 27 months) of nonworking mothers.[2] The smaller N of the working-mother group precluded on age categorization; further, age did not seem to be a relevant factor with this group. Certain family background characteristics were unequally distributed within these groups and may be pertinent to the results obtained. Although the mothers in the nonworking and working groups had similar educational levels, the presence of a father figure was noted more frequently in the homes of the nonworking mothers. On the other hand, the working mothers had to meet the demands of fewer children. Within the nonworking group, the older children had a substantial advantage on two of these factors: fathers were most often found in these homes and the mothers in this group had the highest educational level. These families were, however, considerably larger than either the families of the working mothers or the families of the nonworking mothers of younger children. These data as well as the observational data and the results of standardized tests are presented in Table 1.

Clearly, the participation of mothers who worked on a full-time basis outside the home was inferior in all respects to that of the mothers who were not fully employed. Their attendance was markedly poorer than that of the nonworking mothers whose commitment to program goals is perhaps best shown in the high percentage who elected to participate in a second-year program. Only 33% of the fully employed mothers voted to continue. The nonworking mothers tended to show leadership qualities and attentive interest at the weekly meetings while 50% of the working mothers appeared bored or indifferent. Concomitant with their rather negative response at meetings is the high percentage of working mothers (83%) who were rated as ego-centered or primarily concerned with personal problems rather than the educational goals of the program for their children. Several of these mothers, in fact, tended to exploit the meeting time to verbalize guilt feelings related to their inability "to give to" or "to do for" their children. Finally, only 17% of the working mothers were considered to be innovative in their use of program materials or able to extend the goals of the program through their own initiative. A rather high percentage of the nonworking mothers demonstrated an ability to extend their

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[2] Nineteen months was chosen as the cut-off point for the younger group since half of the twenty children were nineteen months or less at the initiation of the program.

Table 1

Family Background, Observational and Standardized Test Data

Variable	Working Mothers (N=6)	Nonworking Mothers (N=14)	Nonworking Mothers (N=8) Younger Infants	Nonworking Mothers (N=6) Older Infants
Initial CA (in months)				
Range	17 - 22	13 - 27	13 - 19	20 - 27
Mean	19.3	19.2	16.1	23.3
FAMILY BACKGROUND				
Father figure in home	17%	50%	38%	67%
Mean number of children	4.0	5.3	4.1	6.8
Mean educational level of mothers	9.5	9.1	8.8	9.7
MOTHER PARTICIPATION				
Mean absences	10.2	2.5	3.5	1.2
Class participation				
1. Leadership	33%	21%	0%	50%
2. Attentive	17%	64%	75%	50%
3. Bored, indifferent	50%	14%	25%	0%
Ego-centered	83%	21%	38%	0%
Elect 2nd Year Program	33%	93%	88%	100%
Extended activity	17%	50%	25%	83%
MOTHER-CHILD INTERACTION (with program materials)				
Teaching relationship				
1. Highly effective	0%	43%	38%	50%
2. Inappropriative at times	17%	43%	38%	50%
3. Negative	83%	14%	25%	0%
Child's interest	17%	86%	75%	100%
Child's spontaneous verbalization	33%	86%	75%	100%
CHILD PERFORMANCE: PROGRAM TASKS				
Form box: Number of forms (1-5) placed	2.3	3.5	2.6	4.7
String beads	67%	79%	62%	100%
Shapes, colors, sizes	33%	57%	38%	83%
Puzzles	33%	57%	38%	83%
Books	17%	50%	25%	83%
Identifying body parts	50%	57%	38%	83%
Picture lotto	33%	57%	38%	83%
STANDARDIZED TESTS	N IQ CA	N IQ CA	N IQ CA	N IQ CA
Test-one Cattell	3 90.7 18.3	5 104.0 15.5	5 104.0 15.5	
Test-two Cattell	3 86.0 25.0	5 97.4 21.6	5 97.4 21.6	
Test-one Cattell	3 91.3 21.0	9 98.3 21.0	3 98.3 16.7	6 98.3 23.1
Test-two Binet	3 87.3 27.3	9 106.0 28.3	3 109.3 25.0	6 104.3 30.0

teaching skills. It seems fair to conclude that, in spite of verbal support of the program, the six mothers who were fully employed did not have the time or energy to implement program goals or to involve themselves in the group process at a meaningful level.

The participation ratings given to nonworking mothers of older infants were consistently higher than those assigned to nonworking mothers of younger infants. In this instance, it must be assumed that both groups of women had equal time and energy to implement these goals, and the age differences of their children at the initiation of the program may well have determined this disparity in ratings. It is altogether possible that the schedule of activities was more appropriate for the slightly older children and that a productive, rewarding situation for both mother and child was more readily attained. If the activities were somewhat less suited to the younger children, their mothers may have had greater difficulty with teaching assignments and felt less adequate as mother-teachers and program-participants. They may have sensed with considerable accuracy that the program was not immediately relevant to their infants.

The ratings on quality of mother-child interaction observed during home visits closely paralleled the participation ratings assigned to the three groups of mothers. Again, the nonworking mothers of older infants achieved the highest rating, and the attention span and spontaneous verbalization exhibited by the infants in this group was remarkable. The performance of nonworking mothers with younger infants closely followed while that of the working mothers and their infants was markedly inferior. All but one of the six working mothers exhibited an essentially negative teaching relationship. Again, working mothers, regardless of their good intentions, may have been so pressed by family and home responsibilities that they found it difficult to be consistent and patient with their infants.

The observational data from the third category, child performance on program tasks, generally support the data from the other two categories. Performance on these tasks by the children of working mothers uniformly fell below that of the children of mothers who were not employed on a full-time basis outside the home. Their performance, in fact, was no better than that of the younger infants of nonworking mothers. The mean CA of the children of working mothers was, in fact, three months greater, a factor which should have been a considerable asset on many of these tasks.

The data from standardized measures of intelligence tend to confirm the implications of the observational data. The children of working mothers scored 9 IQ points lower on the initial Cattell than the children of nonworking mothers. The test-two Binet scores reflect a similar ranking, and these children again scored lower, 19 points below the children of nonworking mothers. The older children of nonworking mothers ranked second on the post-Binet while the younger children of nonworking mothers scored highest on the initial Cattell and on the post-Binet. (The loss in IQ of the five younger children posttested by the Cattell is not supported by other data.)

CONCLUSIONS

Although no substantial conclusions can be drawn from the information provided by the standardized instruments or the observational ratings, certain factors may have had governing importance within employment and age categories. Mothers who worked full-time were not active program participants at meetings or at home. The teaching relationships they established with their infants were inferior and their children generally did less well on program tasks. Finally, on the initial Cattell and on the post-Binet these children ranked lower than the children of nonworking mothers.

The younger children of nonworking mothers scored highest on the initial Cattell and on the post-Binet, and, in spite of their lower CA, did as well on program tasks as the somewhat older children of working mothers. The level of mother participation and the quality of mother-child interaction for this group was clearly superior to that of the working mothers but clearly inferior to that of the nonworking mothers with older infants, a discrepancy which may relate to the developmental nature of the program tasks.

The older children and their nonworking mothers demonstrated the superior performance on all evaluations except the post-Binet where these children ranked second. The high level of participation of these mothers and their commitment to program goals was clearly indicated by their remarkable attendance record, their ability to extend teaching skills in innovative ways, and their 100% endorsement of a second-year program. Their teaching effectiveness is reflected in the interest shown by their children in program materials, in their spontaneous verbalization, and in their consistent mastery of program tasks. It must be acknowledged that this group more often had fathers at home and the highest educational level for mothers. There were, however, more children in these families to compete for the time and attention of the mothers.

The tentative conclusions drawn regarding the effectiveness of this program in training mothers to teach their infants at home suggest several implications for future investigations in this area. In general, mothers employed on a full-time basis outside the home cannot effectively participate, and their children may be better served through day-care placement. The age of the child at the initiation of the program may well be crucial to his progress as well as to the participation level of his mother. Grouping mothers according to the ages of their children within rather narrow limits (three to four months, perhaps) seems essential if appropriate materials are to be chosen and if effective procedures are to be followed. Such closely defined groupings should improve the quality of the at-home instructional program as well as the nature of the group interaction at weekly meetings.

Acknowledging the paucity of "hard" data obtained during the brief interval of this study and recognizing the potential charge of sentimentality, the staff who implemented this program have provided a selection of comments supplied by the mother participants to an "objective" interviewer (a staff member not affiliated with this program) at the final meeting. The responses of ten of the twenty mothers follow:

> I wish they'd had this program when the rest of my kids was coming up.
>
> They should keep the program all the time for other babies. Mothers in this should not stop but keep on doing this with this child and their others to come.
>
> It's been good for the whole family. He's learned the value of things he has to take care of. He follows directions from others too. It's already helping my newest baby. I don't just leave him to play alone now.
>
> The program has changed our whole house. It looks like I have more time. It makes you think more.
>
> Sometimes neighbor children come over and I teach them. I go to other homes to teach mothers how to play with their children. Now some of them can string beads and things. It seems like when someone comes, my boy wants to show them how to do things with the toys.
>
> I have enjoyed it very much. It has helped me and him. He has enjoyed it. It makes him more happy. I learned a lot of things I could teach him.
>
> It helped me a lot. It helped me to learn a lot about my child that I didn't know....how to handle her when she can't have her own way. Usually I'd give in. Now, with the toys, I don't give in. It's taught her she can't always have her own way.

> I learned quite a bit. It should continue. I have nine children and it's helped me know how to help them.
>
> It has changed Cynthia. She was real stubborn. Now she behaves better. She used to be afraid of the teacher. Now she likes her.
>
> It has changed me. I din't use to take up much time with my children, talking to them, or taking them places. Now I take them to the parks and to church. We have a lot of fun.

These comments suggest that this pilot endeavor did indeed foster attitude change, develop self-help skills, and promote a feeling of dignity and worth in the mother-participants. Surely these changes would extend from mother to child. If alteration in the organization and direction within the home can be achieved through training programs involving the mothers of infants, the ghetto child will be given the background of experiences which prepares him for the educational and thereby the economic opportunities of a democratic culture.

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A Sociological Perspective on Counseling Parents with Handicapped Children

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In preparing this paper, we have drawn upon a good deal of published literature concerned with counseling parents of handicapped children, plus our own clinical counseling experiences, and our research with parents in this country and in England. Although our own work has been primarily with deaf children and their parents, we have attempted to direct our remarks more generally, by drawing upon the research of others. Because of the focus of this conference, we will be speaking specifically about counseling parents with very young children.

We have taken a broad definition of counseling in developing the framework for this presentation. We feel strongly that counseling in the formal or traditional sense should be carried on only by professionals who have received extensive generic training and supervision. However, there are relatively few of these highly trained workers, especially if they are also to have special knowledge about various handicapping conditions. In addition, there are many persons who come into contact with families who are not trained to do professional counseling, and do not pretend to be professionally qualified, but who nevertheless serve as informal parent counselors because they are willing and available to answer parents' questions.

Thus, we conceptualized this broader, more informal type of parent counseling as the socialization of parents to a new role. Then we have analyzed the various agents of this socialization, the advantages they may have and the pitfalls they may meet in working with parents. Thirdly, we have enumerated some of the social categories which differentiate parents and influence their needs for counseling. Finally, we will look at some of the "unanticipated consequences" for parents of the trend toward earlier identification of handicaps. By applying this, essentially sociological, framework to a consideration of parent counseling, we hope to provide a perspective for a discussion of this topic.

Parent Counseling as Socialization-- Transition to any new role requires socialization--the learning of new ways of behaving and of seeing one's self. Parenthood itself involves a set of behaviors and attitudes which must be learned. Parenthood, however, "typically offers an adult a series of opportunities for enriching his own identity--opportunities for concrete affirmation of his own generativity, for increased self-knowledge, for vicarious approximation of his ego ideals for experiencing his effectiveness in bringing a productive situation to fulfillment" (Cummings, et.al, 1966, p.595). Persons who have been socialized to this conception of parenthood, through their previous children, and those who are parents for the first time, face a different socialization process when they meet the task as parents of a handicapped child. It has been said that "no parent is ever prepared to be the parent of a handicapped child. The identification of a mother and a father in that role always comes as a painful surprise" (Barsch, 1968, p.9). Although we will offer some modification to this broad statement later, it is certainly true that the socialization to the role as parent of a handicapped child is a transition to an unwanted and distasteful status for most, if not all, who find themselves in this position.

As in other roles, we can differentiate two broad aspects of the role of parent of handicapped child. There are the instrumental, or technical aspects of the role which must be learned, and there are the expressive, or emotional aspects of the role which must be assimilated. (Parsons and Bales, 1955). In terms of the instrumental aspects, examples might be the learning of ways to help a child with cerebral palsy to use his muscles (Schiller, 1961); or learning how to help a deaf child use and regulate a hearing aid. Expressive aspects of this role include learning to deal with feelings of guilt, shame and sorrow; learning to deal with responses of pity, rejection, and avoidance from neighbors (Begab, 1956; Ross, 1963); learning to deal with responses of grief and denial from relatives; with the temptation either to over-protect or to under-protect the child; and learning to deal with the emotional problems which may develop in relation to the disability.

Although it is useful to differentiate these instrumental and expressive aspects of the role of "parent of handicapped child," they are interwoven and mingled. There are expressive aspects of every instrumental task with which a parent must be involved; the parents' ability to solve successfully the expressive aspects of their new role will influence profoundly their ability to perform the instrumental tasks which are necessary for the child. Conversely, the ease with which parents are able to solve the instrumental tasks will influence their emotional response to the handicap. We feel that it is a mistake for the parent counselor to deal only with the technical or instrumental aspects of the parents' role, if he is to be successful in gaining cooperation. The persons who engage in formal and informal counseling with parents may be looked upon as the "agents" of their socialization.

The Agents of Parent Socialization--We can identify five categories of potential agents of socialization for parents of handicapped children. Too often they are concerned with either the instrumental or the expressive tasks of parenthood, and this separation becomes a source of strain to the parent and of additional handicap for the child.

The Physician as Parent-Counselor--In terms of the chronological sequence of events experienced by families with handicapped children, the general practitioner is the person who often begins the process of socializing parents to their new role. Whether he wants this role as agent of socialization, whether he is prepared to perform it effectively, whether parents accept what he has to say, if the physician makes a positive diagnosis, he gives the signal that parents must, embark on a search for a new identity.

The general practitioner is at a particular disadvantage in that he may have inadequate knowledge about a specific disability. In our recent research on deafness in England, we asked parent respondents whether they felt their doctor was very knowledgeable about hearing problems in young children. Ninety-seven per cent responded "No."

The physician as parent counselor may be less effective than either he or the parents would like. There are a number of qualities inherent in the diagnostic situation which lead to an unsatisfactory relationship: the doctor, including the specialist, is usually unprepared or actually unable to give parents the support and/or the information which they most desire at the time of crisis. Using deafness as an example, there are realistic "medical ambiguities" in congenital deafness which mean the physician may be unable either to give a firm etiological report, or a "presecription" which can reverse the child's condition.

Referring again to our English study, we asked respondents what amount of time had elapsed before a firm diagnosis of their child's deafness was made. Twenty-three per cent said, "almost immediately; eleven per cent said, "within six months"; but the remaining (i.e. 65 per cent), replied that diagnosis had taken anywhere from six months to two years or even more.

Parents of handicapped children seem universally to detail dissatisfaction with their physician, whether he has diagnosed mental retardation (Waskowitz,1959), cystic fibrosis (Blumenthal, 1969), brain damage (Barsch, 1961), or deafness (Meadow, 1968).

It is true that parents may tend to project their own feelings of shame and guilt, and deal with them by blaming the physician (Begab, 1966). On the other hand, it seems that parents' complaints are often justified. Their descriptions of medical experiences, even allowing for distortion and expansion, too often reflect the fact that physicians have little or no preparation for recognizing the symptoms of childhood disabilities or for dealing with the feelings of parents during the diagnostic crisis.

The Teacher - Audiologist - Physical Therapist as Parent Counselor--The special educator, the audiologist, the physical therapist, all are essential members of the team which works with handicapped children and their parents. The defined function of these professionals is an instrumental one. They must help parents to understand the reasons for particular regimes, and to learn the techniques required for putting them into effect.

Often, these professionals err by failing to consider only the instrumental needs of parents and child. In attempting to motivate parents to work hard for their child's future technical competence, they may make demands or set standards which parents find difficult or impossible to fulfill. This can set up a cycle of discouragement and despair which can lead to parental paralysis. To strike a balance between motivation and over-expectation, between optimism for the future and false hope which is doomed to disappointment is a very real and difficult problem.

Although the expertise of these professionals lies in their technical, instrumental areas, it is inevitable that they are asked to help provide for parents' expressive or emotional needs. Although it is neither feasible nor desirable for these technical professionals to become qualified counselors or therapists, it would certainly be beneficial for families if they were to have an increased understanding of the expressive needs which their clients have. It is also important for these professionals to be able to recognize the limits of their competency in meeting parents' emotional needs. Sometimes family problems may be sufficiently intense to require referral to psychiatric or psychological resources elsewhere in the community. At other times, these professionals may be able to deal with family concerns with the help, support, and supervision of a mental health consultant. In other situations, it may be desirable to include the mental health consultant as a member of the team which works with parents.

The "Old" Parent as Counselor for the "New " Parent--Most conceptions of socialization include orientation by agents who are presently fulfilling the role. For example, the socialization of children by their age mates, or those only slightly older, is important for understanding childhood (Cooley, 1922). Socialization in professional schools is partially performed by older students who orient newcomers to the expectations of individual teachers, the everyday round, to ways of "making out" in the new situation. The same process occurs in the socialization of the parent of the handicapped child when he meets others either individually or in groups and learns about the feelings and experiences which he can expect from this new and exacting role.

A number of studies of parents with handicapped children have noted the importance which parents attach to their contacts with others in the same situation (e.g. Meadow and Meadow, 1969). Some parents report that these contacts have enabled them to accept their new duties and responsibilities and to find creative ways of fulfilling these tasks. Others stress the emotional comfort which they found in sharing their feelings of bewilderment and sorrow in their new predicament. Some gain hope for their child's future or a more realistic appraisal of his possibilities from these contacts with more experienced parents.

These are some of the ways in which "old" parents can act as useful agents of socialization for "new" parents. Those who have worked through their own emotional reactions to their child's handicap can be very helpful in bridging the gap between the instrumental role socialization performed by some professionals (i.e. the physicians, the teacher, the physical therapist, the audiologist) and the instrumental role socialization performed by professional therapists. Some of the most useful contacts between "old" and "new" parents have taken place in group settings where the mental health expert or professional therapist is available to interpret or to moderate the encounter. This may help parents who may be suspicious, frightened of, or uncomfortable with professionals generally to relate to and accept the kinds of help which can be offered to them.

Not all professionals believe that contact and questions between parents should be encouraged. One teacher, for example, advises parents of deaf children "not to keep asking other people for advice, especially parents of other deaf children (because) all children are different, and their deafness is unlikely to affect them in exactly the same way" (Ling, 1968, p.319). Cooperation between parents and professionals might well alleviate this danger of one family taking the experiences of another as a literal model for their own. It sometimes happens that parents who are the most willing to act as agents of socialization for others and who have the most leisure time to devote to these activities may be threatening to parents who are most in need of someone to bridge the gap between instrumental and expressive agents. They may be better-educated, have different child-rearing values, come from a different socio-economic background. Generally, however, "old" parents can be of great potential value to "new" parents as agents of socialization, especially if they collaborate and work in conjunction with professionals.

The Handicapped Adult as Parent Counselor--The handicapped adult can be seen in two different ways by the new parent of the handicapped child. He can be seen as a reassuring person, as someone who has succeeded in spite of his handicap - and therefore as a person who lessens the intensity of the parent's anxiety and sense of despair. Perhaps his child's handicap need *not* be terribly disabling. A blind man who, through his business acumen has become a millionaire, a deaf-blind person who achieved world-wide fame and respect, a polio victim who became president of the United States -- all are very reassuring figures. The handicapped adult who is functioning adequately and has overcome the debilitating effects of his handicapping condition can serve as an image for the new parent in thinking about his child.

Unfortunately, the handicapped adult can also serve as a negative image. The worst anxieties of the new parent may be confirmed when he comes into contact with a poorly adjusted handicapped adult. Many new parents are not yet ready to face the consequences of their child's handicapping condition at the beginning of the process of their own socialization to the parental role. They may be unwilling or unable to accept the fact that perhaps their child will not be completely "normal" when he reaches adulthood. However, it would seem to be good counseling to help parents gradually come to an acceptance of this possibility fairly early in the child's life.

A team of non-handicapped professionals and adults with varying degrees of disability and varying degrees of adjustment is a variation of this approach. It gives the parent an opportunity to observe the range of adjustment. The team approach may help to demonstrate to the parent that another respected "normal" adult -- i.e. the non-handicapped professional -- is willing and able to work with and respect the handicapped adult.

Although parents find it encouraging to talk to or hear about only the Helen Kellers and the Franklin Roosevelts of the world of the handicapped, they may be building impossible dream castles by excluding ordinary handicapped mortals from their acquaintance. If hopes must be scaled down too greatly as their child matures, the parent counselors who worked with them in the early days have failed them in a very important way.

In the area of deafness, the sad situation of constant controversy regarding methods means that many hearing parents of deaf children are discouraged from meeting and learning to know the many non-oral deaf adults who have made a satisfactory and happy adjustment to life within a deaf community. The stigma placed by society on disabled persons can be overcome by parents and their counselors, but first they must overcome their own feelings of non-acceptance.

The Professional Therapist as Parent Counselor-- Theoretically, the professional therapist should be well-equipped to do an outstanding job in counseling the parent of the handicapped child. The psychological problems, although different in focus, should be amenable to traditional therapeutic techniques. Many therapists do meet the multiple needs of the new parents. However, there are some who are bound by their traditional approach to therapeutic problems and cannot understand why they have not succeeded in their therapeutic task. Many times the new parent requires emergency "first aid" and a flexible approach to his problem. We would characterize this kind of treatment as crisis intervention therapy. A traditional approach involving prolonged contact could in some instance be detrimental. Some recent research (Reid and Shyne, 1969) has indicated that short tern focused therapy for crisis intervention can produce dramatic and effective results. Our experience in working with deaf clients at Langley Porter has been that short term crisis intervention can be very effective (Schlesinger and Meadow, 1968).

The professional therapist needs socialized knowledge in addition to his generic training in order to deal with parents of children with varying handicaps. In addition, he may need some time and some experience to deal with his own feelings about physical handicaps if he has had no direct personal experience in this area. Our work at Langley Porter indicates that many trained social workers and other helping professionals meet the crisis of family deafness with a syndrome which Schlesinger has labeled the "shock-withdrawal-paralysis" syndrome (Schlesinger and Meadow, 1969). Helping professionals may meet a deaf individual, or even a family where only one member is deaf, and suddenly the shock of the encounter causes them to withdraw from the situation, and display a paralysis which prevents them from utilizing their professional skills.

One area which should be explored and developed more fully is that of training individuals who are themselves handicapped to become professionals in the helping area. Although some of these are presently working in the field, much more can be done to further the numbers and the competence which they have for dealing with the parents of handicapped children.

The Recipients of Parent Counseling--It may seem redundant to discuss the question of"who are the recipients of parents counseling?" because the obvious answer is, "Parents, of course." However, there are a number of sociological categories which differentiate parents, and which affect not only their response to a handicapped child, but their need for and acceptance of counseling. Although additional categories can be named, those which we shall discuss are: socio-economic status; age of parents; sex and birth order of the handicapped child; religion; parents' own status as handicapped or not.

Parents' Socio-economic Status--The social and economic status of the parents of a handicapped child has a far reaching effect on both their initial and their long-term response to disability. For example: the higher the social and occupational position of the family, the higher are the expectations for comparable achievement by their children and the greater their disappointment with a child who may well be incapable of realizing their hopes and dreams for him.

A number of authors have noted this discrepancy among parents of mentally retarded children. For example, mothers of high socio-economic status were found to respond to the diagnosis of mental retardation as if to bereavement; whereas mothers of low socio-economic status were found to respond as if to a role crisis (Farber, 1960). Another author found that families with more education demonstrated less interest in their institutionalized mentally retarded child, and also placed children in an institution at an earlier age. He says, "The education experience is a life condition of these families and thereforeplays an important role in determining familial conceptions of what is desirable for children..." the diagnosis of retardation quickly shatters (their) hopes and aspirations" (Downey, 1963, p.192).

The same general picture has been noted among parents of deaf children. Parents of higher socio-economic status had greater expectations for the achievements of their children, and were more disappointed when these were not met. (That these feelings are communicated to the child is suggested in the finding that deaf children from families of higher socio-economic status had lower self-esteem than other deaf children (Meadow, 1969).

In a society where upward mobility and occupational-economic achievement are the norm, it is no wonder that parents of handicapped children "suffer a loss of self esteem;" "experience a feeling of shame;" "anticipate social rejection;" and "show feelings of guilt and self reproach" when they give birth to a child who cannot meet these expectations, (Ross,1963). We feel that the greater the gap between parental expectations and the child's ability to meet them, the greater will be the parents' need for counseling in this area.

The family's lack of economic resources may be a source of additional worry in terms of their handicapped child. One study of families with child polio victims found that "The presence in the family of a handicapped child placed some fathers under greater compulsion to find a better paying job" (Davis,1963, p. 110). The added cost of taking care of a handicapped child may place an economic strain on some families. Recent advances in social legislation and financial assistance to disabled persons are encouraging. However, sometimes the process for obtaining this assistance is cumbersome and creates considerable resentment. We were very much impressed with governmental assistance to the disabled in England where medical care is free and where there is legislation requiring certain employers to hire the disabled. In England, financial assistance is a right and not a privilege. There is little doubt that lack of economic resources in the families of handicapped individuals increases the need for effective parental counseling.

Parents' Age, Child's Sex and Birth Order--The age of the parents may well relate to the handicapped child's sex and his birth order in creating family problems which are amenable to the counseling process.

Farber notes (1960, p.5) that "having a first child in any family disrupts previous family routines and modifies the values of the parents. The parents, however, can usually maintain most of their occupational, friendship and kinship commitments. In contrast, having a severely mentally retarded child frequently creates a situation of utter chaos." The handicapped first-born son of a young couple may create a more severe crisis of disappointed expectations than that of a first-born daughter, or of a later-born son. Our interview with parents of deaf children have shown this to be the case in a great many instances. (For a general discussion of the influence of these variables of family structure on socialization, see Clausen, 1966).

There is a greater chance for an older mother to have a handicapped child. The psychological problems of child rearing are sometimes accentuated with older parents. There is also evidence to suggest that the child born to an older mother may not be as frequently planned or welcomed as is the child born to the younger family. Older parents may worry more about providing for the needs of the handicapped child in later life. These problems in addition to the usual ones accompanying handicap create needs for special kinds of counseling.

Age of parents may well be related to other factors which influence family acceptance of the handicapped child. The very young mother may feel extreme guilt if her handicapped child was conceived out of wedlock. Feeling of resentment, and of "punishment for sin" often seen in any family where there is a handicap, may be increased to a pathological degree in such cases.

Where the handicapped child is the first-born, there may be need for genetic counseling for the family. When other, normal children have already been born to the family, their concern with and guilt about possible hereditary factors will probably be less critical.

Parents' Religious Orientation--The influence of religious orientation of parental acceptance of handicap has been a subject for some speculation and occasional research, but the findings are somewhat contradictory. One study, for example, found that Catholic families were more likely to accept their handicapped child (Zuk, 1959). A study of families of polio victims notes that "One Catholic family...chose to regard (their child's handicap) as a stigma indicative of their son's blessedness and calling to the cloth. It is doubtful whether the parents ever completely resolved their conjectures about their responsibility for the child's illness" (Davis, 1963, p.38). Jordan (1962) has speculated about the possible community support available to the Mormon family with a handicapped child, or to Williamsburg Jews.

The frequent references to guilt, stigma, reduced self-esteem, and shame on the part of parents with handicapped children* would seem to indicate that

*(See, particularly, Thurston, 1960; Babbit, 1964;Liberthson, 1968; Cummings, 1966; Freedman, et al, 1960).

the influence of differing religious orientations might be a fruitful one for additional research.

Parents' Congruent Condition--A final characteristic which differentiates groups of parents, and influences the kind of counseling they may need, is their own status as a handicapped or non-handicapped individual. Research on the reactions of deaf and hearing parents to a diagnosis of their child's deafness indicates that deaf parents adjust relatively easily and quickly to the diagnosis. Their definition of the situation was much different from that of hearing parents, who responded with denial, with trauma, grief, or occasionally, with relief (when they feared a different, even less acceptable handicap had been discovered (Meadow, 1967, pp.253-266).

In writing of the families of mentally retarded children, Begab (1966,p.72) notes that "Clinical observations and findings have focused primarily on the severely impaired or on the less handicapped with central nervous system damage. In nearly all instances, the intellectual disparity between parents and retarded child is marked. The reactions noted bear little resemblance to those in families in which the child's mental endowment approximates that of other members." He observes that the most limited families of retarded children need special assistance from schools and/or public health agencies, in order to be able to deal effectively, not only with the particular child, but with a whole range of health, personal, and social problems of everyday living.

Deaf families with deaf children seem to need particularly sensitive counseling if they are to accept and cooperate wholeheartedly with plans for the child's training. Downs reports (1967, p.26), that of the five infants definitely identified and confirmed as being deaf, in the Colorado program of early testing for hearing, two were the children of congenitally deaf parents and did not participate in the habilitation program because of the wishes of the parents." Our experience at Langley Porter would indicate that this acceptance of technical and psychological help is more likely where counselors feel and demonstrate to the parents their acceptance and respect for the deaf parents' manual communicative mode. Deaf parents, understandably, seem to feel more threatened and less willing to cooperate with training programs which prohibit their everyday form of family communication.

Some "Unanticipated Consequences" of Early Diagnosis A major concern of this conference is that of examining the possibilities for earlier diagnosis of handicapping and potentially handicapped conditions in young children. Anyone who has worked closely with handicapped children cannot but agree enthusiastically that there are great benefits to be gained by children from early diagnosis and treatment. Most of us, too, have talked to many parents whose lives were made miserable by their prolonged search for diagnostic information,by denial of an abnormal condition, by delayed diagnoses for their children.

In our English study, we asked the parents, "Did a doctor ever deny the child's problem was a hearing loss?" Thirty-two per cent said "No". In 22 per cent of the cases the doctor implied that the problem was an anxious mother; in 14 per cent the doctor said the child was normal. For eleven per cent the doctor thought the child was mentally retarded. For eight per cent, the doctor said the child was "stubborn" or lazy." For another eight percent, the diagnosis was in question for a prolonged period.

Support for the current trend in the work toward early identification should not, however, blind us to unanticipated consepuences that develop, in the form of the new problems for parents. Counselors should be prepared to deal with these unanticipated, negative consequences, as well as with the anticipated, positive effects of earlier identification.

The first potentially stressful effect of earlier case finding, from the parents' point of view, is the fact that there may well be a longer time lapse before specialists can say, with certainty, what the precise nature and extent of the child's handicap may be.

For example, in the Colorado infant screening program, a "fairly high rate of false positives is found:...1½per cent of the total fail to respond to the test signal and 97 per cent of these are ultimately cleared" (Downs, 1967, p.26). A prominent audiologist, in discussing early detection of hearing loss, has written, "Although opinions differ regarding the use of hearing aids during early infancy, they are routinely recommended to those children who can profit from their use as soon as hearing levels can be described with reasonable accuracy, *frequently during their second year*" * (Flower, 1968, p.2) A pediatrician (Mantell, 1967) says, "Not every child who fails to respond to sound is deaf" (p.34); "Mental retardation is a condition commonly confused with deafness. The inattention and lack of responsiveness of the retarded child often seems to be inability to hear ......A psychotic or autistic child may first come to our attention because of lack of response to sound or to speech." (p.39). Of the more than 700 children referred to a traveling diagnostic clinic service in Los Angeles, because of suspected mental retardation, 7 per cent were found to be normal, and an additional 14 per cent were of normal intelligence but had a hearing or visual handicap, a behavior or personality disorder, or were suffering from maternal deprivation

* italics added

(Koch,1966, p.52). This was based on experiences with children who were, on the average, between 2½ and three-years-old.

Longitudinal studies of the growth of intelligence reveal that there is "no relation between relative performance in the first few months of life and scores earned at the end of the first year. It is well established that we cannot predict later intelligence from the scores on tests made in infancy" "Bayley, 1955, p. 806).

The point which is important for us here, is that uncertainty is a common factor in any attempt to diagnose a child's handicap. The younger the child, the more likely it is that the diagnosis must be uncertain. Uncertainty, in any human situation of impending tragedy, is difficult to bear. Parents often indicate that it was the uncertainty, or the ambiguity of their child's diagnosis which was most painful in the early days of their involvement with specialists (Meadow, 1969; Davis, 1963). Parent counselors could be most helpful during this early period, and should be prepared to accept and to help parents deal with, these very realistic responses.

Thus far we have been focusing on the uncertainty created for parents by lack of a precise or a differential diagnosis for their handicapped child. However, there is another danger for parents in programs of early identification. This lies in the higher rate of false positive diagnoses which occur when infants are involved. When frequent follow-ups of "high risk" infants are requested by clinics, it seems very unlikely that parents do not realize that the physician is troubled by some symptom in the child. This facet of early identification program for hearing impairment is recognized by Flower, who suggests that

... it is always necessary for the responsible (diagnostician) to strike a delicate balance between constructive concern and panic. If the clinician's concerns are understated, the parents may not seek adequate follow-up evaluations. If overstated, they may become so anxious that the whole parent-child relationship can become grossly disturbed" (1966, p.7).

In recent years, England has maintained an "at risk" register. Attending physicians, midwives, and health visitors have been alerted to the possibility of a handicapped child in the family. However, the advantages of this register are now being questioned, and some county health officers have discontinued its use.

As new diagnostic procedures are developed and perfected, it is important that the instrumental and the expressive agents of parent socialization work together to minimize any negative concomitants of experimental programs for parents, whose new role is difficult at best.

Summary and Conclusions

We have attempted to introduce some sociological concepts, and to apply them to counseling parents of handicapped children. Thus, we have analyzed the parent of a newly diagnosed handicapped child as a candidate for socialization to a new and distasteful role, which has aspects of both an instrumental or technical nature, and an expressive, or emotional kind. From this framework of role socialization,we can see parent counselors as potential agents of socialization, who probably have competencies in either the instrumental or the expressive aspects of the parents' problems. The agents of socialization who were examined were: the physician; the teacher - audiologist - physical therapist; the "old parent", the handicapped adult; and the professional therapist.

Parents, as recipients of parent counseling, differ in a number of important social categories which influence their need for, and ability to accept the counseling which may be available to them. Those which were examined here were variables of socio-economic status; age, sex and birth order; religion; and parents' own handicap.

Finally, we have examined some of the unanticipated consequences for parents of the increasing trend toward attempts to identify and treat the child's handicap earlier and earlier in his life.

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THE INSEPARABLE TWINS: EARLY DIAGNOSIS and PARENT COUNSELING

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While parents have been around for a long time, the first being mentioned in the Fourth Chapter of Genesis, it seems that only recently have they come to the surface in the area of special education. The fact of this session, and others like it at this meeting, signifies growing acceptance of the role of parents in the intricate process of helping exceptional children to become as normal children as possible.

Agreed that for centuries parents of exceptional children were both parents and teachers. Such children were not accepted in usual schools, and so the parents were the only ones left to teach anything that was going to be taught. Today, with special education programs growing by leaps and bounds, there is a tendency not only to accept parents as such but to counsel them in a constructive way on how they can help themselves as well as their exceptional child.

So parent counseling is the coming thing today in professional meetings and in the literature, and the idea of parent involvement is as generally well-accepted as motherhood itself. The tricky question is: What type of counseling, by whom and when?

There's an overpowering impulse today to generalize any bit of minimal data into an entire population. Statisticians live on the technique of taking as small a sample as possible and using it as a basis for drawing conclusions about much larger groups. In trying to adopt these well-known, tried and statistically true techniques to determinations about the needs and the experiences of parents of hearing impaired children, I would like to add my own cautionary note. This is appropriate because in a few minutes I'm going to be quoting figures and maybe implying more than I should. So you remember my warnings even if I don't!

The circumstances surrounding the family with a deaf child seem to me to be diverse enough to make generalizations highly suspect. To try to come up with a national posture of parents of deaf children based upon any of the samples I've collected, or heard of, is denying a wealth of experience that says many of the opinions, if not the facts, are frequently hidden to any but the most clever experienced investigator.

Parents Want Answers

We've often heard it said that all parents want to DO SOMETHING when they find they have a deaf child. They want to get to work on overcoming the handicap which has crept upon their child. The anxiety experienced in not being given anything to do is perhaps the greatest trauma that the conscientious parent of a deaf child faces.

But is it true that all parents have this same reaction? Really, the best we can say is that most of the parents who have responded to selective surveys or who attend organized parent groups seem to have this feeling.

It seems to me that the better way of expressing the needs of parents of young deaf children may be to say that most of them seek some authoritative figure to TELL THEM what they should know and what is right for their particular child. How often have I heard reported,at parent group meetings, frustration and then anger experienced when parents can't find anyone to listen to them and then tell them what to do.

Once some of the original questions have been answered to the initial satisfaction of the parents, there seems to be a tendency to relax and resume that strenuous task of being just plain parents again.

This period of indecision, then, between first suspicion of a hearing loss, accurate diagnosis and prognosis - so often accompanied by incomplete or inaccurate information and absence of an authoritarian figure - seems to stand out as the most trying in the memories of many parents of hearing impaired children and, perhaps, in the memories of all parents of handicapped children.

The figure who looms large in the lives of these families at this time is the medical doctor.

Pediatrics - General Practitioner - Otology

Traditionally the family doctor has been the family friend, counselor, and confidant. The arts of diagnosis and curing illnesses, setting broken bones, mending injured egos, and delivering babies - all have been represented by the kindly physician down the street. Hardly an issue of *The Reader's Digest* goes by without a story about the kindly gentleman whom someone remembers with affection because of his great humanity and service to the community. It is only logical, then, for this same person to be the one to whom a mother takes her baby and asks, "Doctor, is my baby deaf?"

Of course, this situation assumes that the parents have already suspected something is wrong with the child and bring it to the physician for diagnosis or confirmation of their own diagnosis. If we can generalize from a study of 130 families which we did in 1968,[1] this is most often the case. In more than 80% of our respondents we found that the parents or grandparents first suspected that something was wrong with the child, and then proceeded to take it to a doctor for diagnosis. In only 9% of the responses was there an indication that it was the medical doctor who first suspected the problem.

At least with this sample, then, the parents suspected a problem and brought their child to the person who, by tradition and by reputation, was the one who was supposed to have the answers.

Unfortunately, for the physicians involved, many of these parents apparently expected more than a medical diagnosis from him. Yes, they came for tests and an examination of head, ears, throat, nose, and perhaps general physical development. But the responses to our questionnaire reveal that, if that was all they got from their doctor, these parents were bitterly disappointed.

Perhaps they were expecting too much. After all, it's hard to find in one person the education, personality characteristics, and experience of a medical specialist, a teacher, a counselor, a psychologist, a social worker, and maybe a father confessor. We will have to leave with Dr. Jones, who will have an opportunity to react to these papers, the task of establishing the reasonableness of these parent demands on the medical profession.

For the moment I shall only relate what we think we have learned from these two studies as to the relationship between some parents of deaf children and their medical advisors.

If I Had It to do Over

A paper delivered before the annual convention of the Council for Exceptional Children in Denver this year reported on the results of a mail survey of 255 parents of hearing impaired children. The response on this survey and the current one, which I shall describe shortly, was 50%. While I'm not a specialist in survey techniques, I suspect that this is a phenomenal response and perhaps an indication of the aggressive interest of these parents in a study of parent counseling.

I won't take our time here to report the results of this 1968 survey because they have been published.[2] In speaking of these results before groups of parents of deaf children, however, I should say that the universal reaction has been, "When and how are you to give these figures to the physicians?"

1969 Parent Survey

In the 1969 survey, the results of which are being reported here for the first time, there are several qualifications to be made immediately.

These parent responses represent 50% of those to whom questionnaires were mailed. The names came from the records of those who have written or called the Alexander Graham Bell Association for the Deaf at its headquarters, the Volta Bureau, Washington, D. C. This is, therefore, a select sample. Somehow, these parents came into contact with a person or publication which named the Bell Association as a source of information.

Furthermore, these parents had to be able to write, have paper and pen, have a six-cent stamp, and have the interest and the initiative to put down their questions in black-and-white. Each of the parameters could make this sample selective. It probably isn't representative of the great majority of parents of hearing impaired children, although even that is an empirical judgment unsupported by fact. It's just a hunch!

Actually, I suspect that this sample represents the highest end of the scale of parents. Not only did they have the paper, pen, and the six-cent stamp, they all indicated they had seen at least one physician. This more or less establishes a socio-economic status and cultural concern for the health of their children.

If anything, we might be impelled to say that these parents had the best chance for proper diagnosis and counseling. By inference, then, we might be able to say that there are many others whose experiences were far worse than these.

Now,for some of the specifics.

We received exactly 100 responses from the mailing of 200 questionnaires. Actually, there were a few more than 200 sent by first-class mail, and the difference represents those letters which were returned to us for non-delivery.

52% of the children were between the ages of 5 to 8 years. The remainder, 48%, were between the ages of 1½ to 4½ years.

In an effort to try to establish in a rough way the distance between these families and some reasonably large urban center, we asked the respondents to say whether they lived within 50 miles of a city of 100,000 or more. 73% reported that they lived within a 50-mile radius of such a center. Our sample, therefore, would not appear to represent families way out in the boondocks.

An empirical analysis of the questionnaires from those living more than 50 miles out in the country failed to reveal any striking evidence of poorer services or counseling to these particular parents.

We first tried to find out what kind of medical specialists these parents had first approached. In the previous study, we used the terms "professional" or "specialist" and found that the respondents didn't always differentiate between an M. D. and a Ph. D. or even an Ed. D. Thus we asked what kind of doctor was first seen, and found:

Pediatrician	44%
General Practitioner	35%
Otologist	19%
"Clinic"	2%

I've heard it said, and I'm sorry that it's only conversation, that across the United States only about 25% of the children are seen by pediatricians. If so, then these facts would tend to support the feeling that this was an above-average sample.

After establishing the type of medical specialists to whom they took their child, the parents were asked if the doctor offered them any suggestions as to what they could do AS PARENTS to help their own child. Here we were trying to pursue the assumption that most parents want to DO SOMETHING, not just be patted on the head and told to leave it all up to the teachers or therapists. We found that one-third of the doctors told the parents there was nothing they could do or gave them suggestions which the parents immediately recognized as ill-informed. For example, here are some direct quotes:

"Just wait."

"Take out his tonsils and he'll be o.k."

"He said J. was nerve deaf and there was nothing to do. It was a terrible blow."

"Early education isn't necessary."

"Don't do anything. She'll talk when she's ready."

Only a fourth of the parents reported positive suggestions for them to follow at home, such as:

"Talk to him."

"Play records, read stories, keep talking."

"Get in touch with the Tracy Clinic."

"Here's a book and pamphlets to take home and read."

"Write to the Volta Bureau."

The remainder of those in the sample were referred to other specialists and/or speech and hearing clinics for further diagnosis or therapy.

We tried another approach to determine if parents were satisfied with the steps they had taken and the treatment they had received in this critical period of diagnosis and adjustment. We asked the question: "If you had it to do over, would you do anything differently?"

Here we were trying to give the parents a chance to look back - to imagine that they were starting on the path at the beginning and,knowing what they know now, chart a different course.

25% said they wouldn't do anything differently. When all was said and done, they had to admit that they had done the best they could and, if given a fresh start, they wouldn't do anything differently.

Almost 30% of the parents said they regretted not having started sooner. From some there were statements like:

"I would have gone to a doctor sooner."

"I'd have accepted the doctor's diagnosis instead of thinking he didn't know what he was talking about."

> "Lipreading lessons would have started at least a year sooner."

> "I'd have sent her to a boarding school sooner."

Some of these parents felt they would be more persistent in getting hearing tests and in getting a hearing aid on their child:

> "I would be much more aggressive and not so trusting of the professionals."

> "I would insist on a hearing test sooner."

> "I would not be pacified by the statement that he's too young to be tested."

> "I would have been more persistent with the doctors."

About 15% said they would have seen a different kind of doctor. Here, there cropped up a comment that we found in the 1968 survey. Many parents felt that, when they finally reached an audiologist, in a speech and hearing center or elsewhere, they began to get accurate facts, attention to their concerns, and some positive recommendations. Some parents even expressed the wish that they could short circuit the otologist and get to the audiologist first. The feeling expressed seemed to be, "We knew he was deaf; and, rather than medical verification, we wanted to know what to do next."

Among the "miscellaneous" category were statements that the parents wished they could have met other parents sooner and that they had learned sooner of the Alexander Graham Bell Association for the Deaf.

Again trying to get at concerns and opinions by letting the parents extract themselves from their current problems by looking backward, we asked them if their concerns about their children were much different than they were one or two years ago.

Again a 25% group said, "Yes, we are less concerned than we were." Their children were in good programs, and things were "settling down".

> "He is learning and understanding."
>
> "We moved to another community, and now he's in a good program."
>
> "I didn't realize she could learn so fast."
>
> "He's in a residential school now and is happy to be there and happy to be home."
>
> "I have less tension now because my husband finally left us after we moved here and things are more peaceful now."

A large group (35%) reported that they now were concerned about educational problems. These ranged from decision on residential versus day school, and public school versus school for the deaf, to the child's ability to communicate with others in kindergarten and a concern on his slowness in reading.

The remainder of the new concerns were covered by new problems in adjustment to school and the family, and discipline. Looking ahead to adjustment in adulthood began to worry some farsighted parents even though none of the children in the sample was more than 8 years old.

Conclusions

So what, if anything, can we conclude about this sample of parents of deaf children. Without trying to extrapolate to a larger population, yet recognizing from our empirical knowledge that some such extension is possible, I offer the following:

* Based upon this study and the previous one, parents are pretty good amateur diagnosticians or at least suspectors of problems. Physicians would do well to listen to parents more closely.

* Parents want and expect prompt, accurate diagnoses of their children's impairments. Many parents can spot a phoney or inaccurate diagnosis while it's happening in the doctor's office!

* As a part of the diagnostic work-up, parents demand knowledgeable counseling on their role in helping their child, on educational opportunities, on hearing aids, and the social implications of hearing loss. They don't want to be put off! On the other hand, they may reject too negative a prognosis if their child is very young.

* Once their child is in some kind of educational program, things begin to settle down - problems don't

disappear, but they seem to be able to be taken in stride. In this, they seem to have found the authority figure that is saying, "I can help you and your child."

- * Inadequate diagnoses and counseling can take place in urban areas as well as in rural areas.

I would hesitate to generalize, too, on the basis of these 100 parents, but I suspect we'll be inclined to so so, based upon our own individual experiences. And we may not be all that far off the mark if we do!

FOOTNOTES

[1] Fellendorf, George W. and Harrow, Icie; "If I Had It to Do Over", CEC Convention Selected Papers, 1969. Washington D. C.: Council for Exceptional Children, pp. 108-118.

[2] Fellendorf, George W.: "If I Had It to Do Over", Exceptional Children, September, 1969, Washington, D. C.: Council for Exceptional Children.

OTHER REFERENCES

McDonald, Eugene T.; Understand Those Feelings, Pittsburgh, Pa.: Stanwix House, Inc., 1962.

Barsch, Ray H.; The Parent of the Handicapped Child, Springfield, Ill.: Charles C Thomas, 1968.